

Report on research, co-design and community engagement to inform the National Roadmap to Improve the Health and Mental Health of Autistic People

Appendix B:

Intersectionality matters research review

March 2024



Report on research, co-design and community engagement to inform the National Roadmap to Improve the Health and Mental Health of Autistic People:

Reimagining health and mental health services for Autistic people, their families and carers

Appendix B:

Intersectionality matters research review

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Autism CRC

Autism CRC is the independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum. Autism CRC provides the national capacity to develop and deliver evidence-based outcomes through our unique collaboration with autistic people, families, professionals, services providers, researchers, and government, together addressing agreed needs and co-producing outputs with these stakeholders for the benefit of the community.

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We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, we use the terms ‘autistic person’, ‘person on the autism spectrum’ or ‘person on the spectrum’. The term ‘autistic person’ uses identity first language, which reflects the belief that being autistic is a core part of a person’s identity. In this document, we are using ‘Autistic’ as a proper adjective or noun. This is the preferred language of the Australian Government Department of Health and Aged Care, and the Autism Health and Mental Health Roadmap Working Group.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the health care sector and is used in the context of a person being ‘diagnosed with Autism Spectrum Disorder’.

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Call: 1300 308 699

Website: lifeline.org.au

Lifeline Australia

Call: 13 11 14 or

Text: 0477 13 11 14

Live chat: lifeline.org.au/crisis-chat

Website: lifeline.org.au

Beyond Blue

Call: 1300 22 46 36

Live chat: beyondblue.org.au/support-service/chat

Website: beyondblue.org.au/

Kids Help Line

Call: 1800 55 1800

Live chat: kidshelpline.com.au/get-help/webchat-counselling

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Website: qlife.org.au/

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1. Executive summary

1.1 Why we did this work

The Australian Government has committed to the development of a National Roadmap to Improve the Health and Mental Health of Autistic People (also referred to as the “Roadmap”). The aim of the Roadmap is to address issues faced by Autistic people in the health care system, and outline actions to improve outcomes. This is being informed through a collaborative research and co-design process. This report forms part of the research component of this process.

This research included secondary analysis of several existing national data sets, which combined information from over 6,500 Autistic people, families, carers and professionals (see section 1.2 for the demographics within each dataset). This foundational stage provides an opportunity to maximise the utility of relevant knowledge, insights and experiences already shared. It also ensures discussions in co-design and community engagement build upon what is already known and understood, allowing a deeper exploration of challenges, experiences and ideas for change.

1.2 What we did

The work within this report was undertaken by a team of Autistic and non-Autistic researchers from **Griffith University**. Four existing datasets were analysed to (a) identify the proportion of respondents in the dataset who identified as being a member of the specified priority groups, and (b) report on the health or mental health care experience data for that specific priority group. The priority groups were identified by the Department of Health and Aged Care and Roadmap Working Group and are:

- Women and girls
- LGBTIQ+ people
- People who live in rural and remote areas
- People who are from low socio-economic backgrounds
- Culturally and linguistically diverse people
- First Nations people
- People with high or complex disability needs, including those
 - with high communication needs
 - with high behaviour support needs
 - living in residential settings
 - with intellectual disability
 - who are non-speaking.

The four existing datasets were:

(1) **The “1,000 insights” community views online survey.** This survey was conducted by Griffith University, for Autism CRC, as part of the landscape mapping report for the National Autism Strategy. Autistic research team members, and Autistic advisors from Autism CRC, co-designed the survey and/or provided feedback on its design. Over 1,000 respondents provided their perspectives via the survey; 42% of respondents were Autistic people, 56% were family members or carers of Autistic people, 18% were allied health professionals, and 10% were mental health professionals. Note that these percentages equal greater than 100% as some respondents belonged to multiple groups (e.g., Autistic and a mental health professional). The survey asked respondents to identify the problems experienced by Autistic people when accessing physical health care and mental health care services in Australia. Respondents also shared their thoughts on what is causing these problems, what could prevent or reduce these problems, and what is working well or has worked well for Autistic people when accessing physical health care and mental health care services. For this project the data from the Autistic respondents was extracted and reported upon by priority group (e.g., Autistic and LGBTIQ+, Autistic and First Nations). Given the range of factors reported across the priority groups, for each group we have focused on highlighting the top 10 most frequently reported factors for each question. On some occasions, fewer than 10 factors are identified, as only those factors endorsed by 5% or greater of the priority group were considered representative of the group.

(2) Anonymised data from the **Autism Connect helpline** (a free, national Autism helpline designed by Amaze) relating to physical health or mental health. This is a dataset of almost 4,500 contacts which relate specifically to health care from all states and territories of Australia, from 2019 to mid-

2023. For this work, each query has been individually coded and summarised for each priority group. As limited or little information was recorded on demographics, the coding focussed on the person the contact was about rather than the person making the contact. It is important to note that it is unknown what percentage of these contacts were made by Autistic people.

(3) Griffith University project data on **barriers to accessing acute health care** (“Barriers to care” questionnaire). This questionnaire asked parent/caregiver respondents to rank predetermined statements relating to barriers to accessing acute physical health care. This reports on the barriers identified by 107 parents and caregivers of Autistic Australian children aged 3 to 16 years.

(4) Griffith University project data on **therapy and mental health care experiences** (“Making therapy better”). This reports on the views of 130 Autistic adults from Australia regarding what could improve their therapy and mental health care experiences.

1.3 What we found

The critical takeaway of this report is that **intersectionality matters**. For each priority group, there were substantial differences in what they identified as the key problems/barriers that Autistic people face when accessing physical health and mental health services in Australia. There were also differences in what each priority group identified as possible solutions.

Whilst informative, this report does not, and could not, report on all of the issues or experiences with physical and mental health care services experienced by each priority group of Autistic people. This report also does not describe the impact of these different experiences on health and mental health outcomes for Autistic Australians, as this was not collected within the datasets. However, what this report can do is provide clear evidence for the importance of listening to the experiences of Autistic people with intersecting identities to inform improvements and pathways for the Roadmap. This report can also be used as a platform to inspire and inform more detailed, in-depth consultations with priority groups to learn about their experiences into the future.

A second key takeaway is that the four datasets provide clear evidence for an **urgent need for improvements in Autistic people's access to physical and mental health care** which take into consideration people's intersecting identities, **and for health care providers with knowledge of autism and intersectionality, and who are skilled in neurodiversity-affirming approaches**. This urgent need is highlighted through the Autism Connect data; in under five years, 1,500 people have contacted Autism Connect asking for their help in finding somebody to support an Autistic person's physical health or mental health. This represents 85% of the contacts with Autism Connect relating to physical health or mental health summarised within this report. This urgent need is also supported by the "1,000 insights" community views survey data, where almost half of all the respondents highlighted that the biggest problem for Autistic people trying to access physical or mental health services is a lack of health care providers or a lack of health care providers who understand autism/neurodiversity. The Roadmap has the potential to address this. In doing so it can begin to reduce the physical health and mental health inequities experienced by Autistic people across Australia and, using this report and the future in-depth consultations, address the specific barriers or problems faced by Autistic people from the Roadmap priority groups.

A summary of the key findings for each priority group and the comparison to the entire Autistic sample for that dataset is presented below and is discussed in detail in the corresponding section of the report. Whilst each priority group is presented separately in this report, it is important to acknowledge that people are complex. Many Autistic people have multiple intersecting identities, and reporting on individual priority groups does not account for these overlapping experiences.

1.3.1 Autistic women and girls

There were six items where the data for Autistic women and girls differed from that of the entire sample of Autistic people. A number of these centred around the need for physical and mental health care professionals to have enhanced training and knowledge in autism and other neurodivergent conditions, and how autism (or other neurodivergent conditions) can present.

1.3.2 Autistic LGBTIQ+ people

There were 25 items in which the data on health care experiences for Autistic LGBTIQ+ people that differed substantially from the entire Autistic sample. The items that Autistic LGBTIQ+ people were more likely to highlight were spread across a number of the areas, including:

- health care practitioners needing more training and information on autism
- adjustments and accommodations (e.g. to the physical environment, communication methods, approaches) are not being offered to Autistic people, when these would be beneficial
- physical health care systems are based on neurotypical/majority needs and therefore do not take into account needs or preferences of Autistic people
- that health care works well for them when they understand what is best for oneself and advocating for this.

Fewer Autistic LGBTIQ+ people identified problems with funding of autism training and of resources compared to the entire Autistic sample. Funding for autism training and resources was nevertheless important to Autistic LGBTIQ+ people. As noted later in this report, 20% of Autistic LGBTIQ+ respondents to the “1,000 insights” community views survey noted lack of funding for autism training and resources as a cause of problems with physical health services.

1.3.3 Autistic people from regional, rural, or remote areas

There were 20 items in which the data on health care experiences for Autistic people living in regional, rural, or remote areas differed substantially from the entire Autistic sample.

The majority of items that differed from the entire sample of this priority group tended to focus upon:

- the limited availability of physical and mental health care practitioners
- limited autism knowledge in physical health care practitioners and limited training or education on autism for mental health care practitioners
- affordability of services and impacts of funding limitations.

Given the prominent challenges in finding and accessing practitioners, it is understandable that Autistic people in regional, rural and remote settings were less likely to focus upon specifics within appointments or settings (e.g. sensory environment, accommodations or modifications) than was noted for the entire sample within the dataset.

1.3.4 Autistic people from low socio-economic backgrounds

There were 42 items in which the data on health care experiences for Autistic people from low socio-economic backgrounds differed substantially from the entire Autistic sample within each dataset. This highlights the importance of considering socio-economic status when exploring physical and mental health care experiences of Autistic people and the importance of deeper consultation to discover more about these experiences. These items tended to focus upon the following areas:

- limited accommodations or assistance provided to support access to services
- the therapeutic skills of physical and mental health care practitioners and the focus on the medical model of disability

- pragmatics and practicalities of attending appointments, clinics or hospitals
- limited knowledge of autism in physical health care practitioners and limited training or education on autism for mental health care practitioners
- affordability of services and impacts of funding limitations
- the need for government reform to change or improve their physical and mental health care experiences.

When compared to the entire sample of Autistic people, twice as many Autistic people from low socio-economic backgrounds said that “nothing” is working well for them in mental health care settings.

1.3.5 Autistic people who are culturally and linguistically diverse (CALD)

There were 49 items in which the data on health care experiences for Autistic culturally and linguistically diverse people differed substantially from the entire Autistic sample within each dataset. This large number of substantial differences shows the broad and wide-reaching impact of intersectionality on the physical health and mental health care experiences of Autistic people in Australia and the importance of further consultations to discover more about these experiences. The 49 substantially different items tended to focus upon the following areas:

- challenges with some health care professionals’ approaches, including ableism or not using neurodiversity-affirming approaches
- limited accommodations or assistance provided to support access to services
- the importance of Autistic (e.g. advocates, Autistic employees) or family input into sessions or services
- the need for government support or reform, including funding, to change or improve their physical and mental health care experiences
- the need for mental health practitioners with knowledge of autism and the importance of autism training mental health practitioners to ensure they use autism-specific approaches to assessment or therapy.

1.3.6 Autistic First Nations people

There was limited representation of Autistic First Nations people within the datasets. This highlights an urgent and critical need for community consultations with Autistic First Nations people to ensure their health and mental health care experiences are considered in the the Roadmap.

1.3.7 Autistic people with high or complex disability needs

There were 55 items in which the data on health care experiences for Autistic people with high or complex disability needs differed substantially from the entire Autistic sample within each dataset. As noted for other priority groups, this large number of substantial differences shows the broad and wide-reaching impact of intersectionality on the physical health and mental health care experiences of Autistic people with high or complex disability needs. This, combined with the small number of

people representing Autistic people with high or complex disability needs in the existing datasets, underscores the importance of further consultations to discover more about these experiences. The 55 substantially different items tended to focus upon the following areas:

- Communication, including the option for multiple modes of communication, ensuring that all people communicating (be that the Autistic person or a family/carer) feel heard, believed and valued, and health care providers asking questions to gain from the experience of the Autistic person or their supporters
- Limited accommodations or supports made to support access to services
- The importance of finding health care services and then developing a good relationship with a practitioner with the skillset to work with Autistic people with high or complex disability needs.

For mental health services, twice as many Autistic people with high or complex disability needs said that nothing was working (although it is important to note that this was based on only 10 respondents to that question). However, for physical health services, substantially less Autistic people with high or complex disability needs said that nothing is working. Studies including greater numbers of Autistic people with high or complex disability needs are required to confirm these findings.

1.3.8 Summary of substantial differences across priority groups

Table 1 and Table 2 combine specific items explored in the datasets to synthesise the key or overarching areas for change or improvement identified across the datasets. These highlight (1) the broad-reaching impacts of the challenges that Autistic people experience when accessing physical and mental health care, and (2) the complex impact of intersectionality. This complex impact of intersectionality needs to be further understood through in-depth consultations with community members. These will be critical to ensure that Autistic people, and their supporters', experiences shape and inform the Roadmap and therefore, the pathway to better health and mental health outcomes for Autistic people.

In the tables below (Table 1 and Table 2), the cells have been shaded to indicate where there are substantial differences in the responses from the priority groups and the entire sample of Autistic people that was available in the datasets. It is important to note, however, that the reasons why these topics may have been more or less reported by a priority group cannot be inferred from this table. There are many potential explanations for this that require further research to understand more fully. As such, caution should be taken so that these findings are not overinterpreted.

The cells are shaded in green and marked with a > symbol when the priority group data showed a significant increase from the broader sample (i.e. more people within the priority group identified significant problem/barrier, or more people from the priority group rated it as something that would improve health care experiences).

The cells are shaded in red and marked with a < symbol when the priority group data showed a significant decrease from the broader sample (i.e. less people within the group identified significant problem/barrier, or less people from the priority group rated it as something that would improve health care experiences). It is important to note that red and marked with a < symbol does not mean it is not an issue for this priority group, but that it was just not as highly rated/ranked as an issue for this group.

Table 1: Areas of physical health care reported or indicated as a problem or area that needs improving, presented by priority group

Category	Areas	Women and girls	LGBTIQ+	Regional, rural, and remote	Low socio-economic background	Culturally and linguistically diverse	First Nations	High or complex disability needs
Professionals	Autism knowledge of professionals needs to be enhanced			>	>		-	
	Better quality, and access to, autism education and training for professionals is needed	>	>		<	<	-	<
	Therapeutic skills of professionals (inc. not believing client) need to be enhanced		>		>	>	-	>
	Having a doctor fluent in the client's native language is beneficial						-	<
Seeking information (as reported in Autism Connect Data)	Contacted helpline to find health professional beyond GP		>				-	>
	Contacted helpline to find a paediatrician		<				-	<
	Contacted helpline to find a professional to support nutrition or dietetics	<					-	<
	Contacted helpline to find a General Practitioner						-	>

Legend:

< Substantially lower item endorsement

> Substantially greater item endorsement

- Insufficient data

Category	Areas	Women and girls	LGBTIQA+	Regional, rural, and remote	Low socio-economic background	Culturally and linguistically diverse	First Nations	High or complex disability needs
Access	Better availability of professionals is needed (inc. waitlist, number of professionals)	<			>	>	-	
	Service access should be supported using a range of strategies (inc. improved communication, flexibility, supports, clear outline of what to expect, transport)		>	<	>	>	-	>
	Report that health care works best when clients find the right professional for their needs and preferences		>			<	-	>
Services	Adjustments and accommodations to services and therapy are needed to support Autistic people	<	>	<	>	>	-	>
	Improved pathways to comprehensive autism diagnosis are needed				>		-	
	Sensory elements of the service environment (e.g., lighting, noise) should be considered					<	-	>
	Concerns regarding the availability or provision of a thorough medical examination				>		-	

Legend:

< Substantially lower item endorsement > Substantially greater item endorsement - Insufficient data

Category	Areas	Women and girls	LGBTIQ+	Regional, rural, and remote	Low socio-economic background	Culturally and linguistically diverse	First Nations	High or complex disability needs
Funding	Affordable services (inc. low cost, funding access) are important		<	>	>	>	-	>
Approach	Concerns about the use of a medical model approach; preference for neurodiversity affirming approach		>		>	>	-	>
Government	Call for government reform, support, and guidance to support access and use of health care services				>	>	-	>
Other	Support of family, advocates, and community is important and/or beneficial					>	-	
	It is important to consider how autism characteristics (e.g., communication, processing, social interaction differences) can impact service access and use						-	>
	Meeting the needs of other family members can pose a barrier to health care access					>	-	
	Nothing is working in the physical health care service	<	>		>	>	-	<

Legend:

< Substantially lower item endorsement > Substantially greater item endorsement - Insufficient data

Table 2: Areas of mental health care reported or indicated as a problem or area that needs improving, presented by priority group

Category	Areas	Women and girls	LGBTIQ+	Regional, rural, and remote	Low socio-economic background	Culturally and linguistically diverse	First Nations	High or complex disability needs
Professionals	Autism knowledge of professionals needs to be enhanced	>			<	<	-	<
	Autism education (quality and access) available for professionals		>	>	>	>	-	>
	Therapeutic skills of professionals (inc. excluding/not believing client)			>	>	>	-	>
Seeking information (as reported in Autism Connect data)	Contacted helpline to find non-psychology mental health professional				>			
	Contacted helpline to find psychologist			>	-		-	<
	Contacted helpline to find psychiatrist			<	-		-	>
	Contacted helpline to find support worker related to mental health				-	>	-	
	Contacted helpline to find assistance with a specific goal or support related to mental health			>	-		-	
	Contacted helpline for mental health advice				-	>	-	

Legend:

< Substantially lower item endorsement > Substantially greater item endorsement - Insufficient data

Category	Areas	Women and girls	LGBTIQA+	Regional, rural, and remote	Low socio-economic background	Culturally and linguistically diverse	First Nations	High or complex disability needs
Access	Better availability of professionals is needed (inc. waitlist, number of (neurodivergent) professionals)		<	>	>	>	-	<
	Availability of services needs to be increased				<	<	-	>
	Service access should be supported using a range of strategies (inc. improved communication, flexibility, supports, clear outline of what to expect, transport)		>		>	>	-	>
	Report that health care works best when clients find the right professional for their needs and preferences				<	<	-	
Services	Adjustments and accommodations to services and therapy are needed to support Autistic people		>			>	-	>
	Improved pathways to diagnosis (inc. services offering diagnosis, less misdiagnosis, acceptance of self-identification) are needed		>	>	>	>	-	>
	Sensory elements of the service environment (e.g., lighting, noise) should be considered		>			>	-	
	Clients experience mistrust in mental health service						-	>
	Care should be Autistic- or research-informed					>	-	

Legend:

< Substantially lower item endorsement > Substantially greater item endorsement - Insufficient data

Category	Areas	Women and girls	LGBTIQA+	Regional, rural, and remote	Low socio-economic background	Culturally and linguistically diverse	First Nations	High or complex disability needs
Funding	Affordable services (inc. low cost, funding access) are important			>	<	>	—	<
Approach	Concerns about the medical model approach; preference for neurodiversity affirming approach		>		>	>	—	>
Government	Call for government reform, support, and guidance to support access and use of health care services					>	—	
Other	Support of family, advocates, and community is important and/or beneficial				>	>	—	>
	Client's understanding and advocating for what is best for themselves enhances their service experience		>		>		—	>
	Experiences and roles of family/parents should be considered and supported					>	—	
	Nothing is working in the mental health care service		<		>	<	—	>

These tables summarise the findings from a range of datasets, however they are not able to explain why these differences occurred. More research is needed to fully understand these findings. Caution should be taken to not over-interpret these tables.

Legend:

< Substantially lower item endorsement > Substantially greater item endorsement — Insufficient data

1.4 What happens next?

The nuanced understanding of why these health care experiences may be reported more or less frequently by or in relation to Autistic people with intersecting identities, and more importantly, the impact of these experiences on health or mental health outcomes, cannot be inferred from these data alone. In-depth consultations with Autistic people who identify with these priority groups are being undertaken to gain this information and will be reported upon separately in a future report. These data and insights can then be combined with information from those working in health care settings so as to identify actionable changes that lead to improvements. It is this collaborative, multi-informant approach that can identify pathways to change and enhance the physical and mental health outcomes for Autistic Australians now and into the future.

2. Method

2.1 Context

The Department of Health and Aged Care is developing a National Roadmap to Improve the Health and Mental Health of Autistic People (also referred to as the “Roadmap”). This is being informed through a collaborative research and co-design process. This report forms part of the research component of this process.

2.2 Aims

This research aimed to undertake secondary analysis of several existing national datasets to maximise the utility of relevant knowledge, insights, contributions and investments. It also reduced project risk and consultation fatigue within groups who have recently shared their views on these issues and ensures the discussions in future stages build upon what is already known.

The research aimed to explore the existing datasets to identify the health and mental health care service experiences of Autistic people who identify as belonging to the seven priority groups identified by the Department of Health and Aged Care and Roadmap Working Group. These priority groups are:

- Women and girls
- LGBTIQ+ people
- People who live in rural and remote areas
- People who are from low socio-economic backgrounds
- Culturally and linguistically diverse people
- First Nations people
- People with high or complex disability needs, including those
 - with high communication needs
 - with high behaviour support needs
 - living in residential settings
 - with intellectual disability
 - who are non-speaking.

2.3 Datasets coded

To maximise data already collected that report on health or mental health service experiences of Australian Autistic people, this report explores data from four existing datasets. For each dataset, the data from Autistic people (or from people providing insights on behalf of Autistic people e.g., Autism Connect contacts), from the predetermined priority groups were identified and reported. To aid interpretation as to whether these are issues that many Autistic people experience, or if they are more prominent, relevant, or specific to Autistic people within a particular priority group, the data for each priority group are presented alongside data from all Autistic people.

2.3.1 The “1,000 insights” community views survey

For a full description of this survey and analysis of all results (including the data and perspectives of medical professionals and allied health professionals, which are not included in this report), see Adams et al. (2023) (autismcrc.com.au/research-evidence-and-policy-landscape-mapping).

In brief, an online survey was used to capture the thoughts and perspectives of the Autistic community and other relevant stakeholders (e.g., families/carers, teachers, medical professionals, allied health professionals) on a range of service domains. The two service domains reported upon in this document are (a) physical health services, and (b) mental health services. Additional domains included diagnosis, early intervention and support, education, employment, housing and independent living and justice.

This survey was co-designed with researchers, Autistic advisors, and Autistic and non-Autistic Autism CRC staff. The survey invited people to answer four questions for each of the service domains, with some aspects tailored to the specific domain:

1. What are three problems that Autistic people experience within this service domain?
2. What do you think is causing these problems?
3. What do you think could prevent or reduce these problems?
4. What is working well, or has worked well, for Autistic people within this service domain?

People sharing their insights were able to provide responses for as many service domains as they wished. Within each domain, the person answered the questions using their own words (i.e., they were not given tick boxes or predefined options to select from). This ensured the answers would come from the community rather than being those predefined by the research team and/or their advisors. Each respondent's response was read, and the first three issues raised in each answer were coded using inductive content analysis.

For this report, only the data from Autistic people ($n = 253$) are reported. This is because we are using the respondent demographics to identify whether the respondent belongs to any of the priority groups, and therefore may be more likely to be reporting on issues experienced by their belonging to a particular priority group.

The survey received full ethical approval from Griffith University on 3rd March 2023. Data were collected between March and May 2023 and analysed by both Autistic and non-Autistic researchers.

2.3.2 Anonymised Autism Connect helpline data

Anonymised data from the **Autism Connect helpline** (a free, national autism helpline designed by Amaze) relating to physical health or mental health were analysed. Amaze identified almost 4,500 contacts which may relate specifically to physical and mental health from all states and territories of Australia from 2019 to mid-2023.

For this report, the data from each of the 4,500 contacts was reviewed and coded. These were firstly coded into physical health topic, mental health topic, or unclear. Those identified as relating to physical health ($n = 292$) or mental health ($n = 1,514$) were then, based on the description of the communication, further coded into more specific categories. These were then summarised for each priority group in the sections below. As limited or little information was recorded on demographics,

the coding focussed on the person the contact was about rather than the person making the contact. It is important to note that it is unknown what percentage of these contacts were made by Autistic people.

2.3.3 Barriers to acute physical health care survey data from parents of Autistic children

A Griffith University Masters student collected data on the **barriers to accessing acute physical health care** for Autistic people using a standardised “Barriers to care” questionnaire. These data report on the barriers identified by 107 parents and caregivers of Australian Autistic children aged 3 to 16 years. This questionnaire provided parent respondents with 39 predetermined statements which consider pragmatics such as logistics and cost (9 questions), skills to navigate the health care system (8 questions), expectations of care (7 questions), marginalisation within the health care system (11 questions), and knowledge and beliefs (4 questions). Parents and carers indicate their agreement with these statements using a 1-5 scale, where a lower score indicates a smaller barrier.

The study received full ethical approval from Griffith University on 17th March 2022. Data were collected throughout 2022 and analysed by both Autistic and non-Autistic researchers.

2.3.4 Autistic people’s perspectives on how to make psychological therapy better

Researchers from Griffith University have previously collected data from 130 Australian Autistic adults regarding what, from their perspective, could improve psychological therapy. This questionnaire was co-produced by Autistic and non-Autistic researchers. It consisted of 55 items, each considered a possible adaptation to psychological therapy. The respondents then rated the potential impact of the adaptation on the experience of psychological therapy using a Likert scale (1 = not at all helpful; 5 = extremely helpful).

The study received full ethical approval from Griffith University on 27th March 2023. Data were collected from 28th March 2023 to 23rd May 2023, and analysed by both Autistic and non-Autistic researchers.

2.4 Representation of Autistic people from the priority groups within the datasets

Tables 3-1 and 3-2 report the number of Autistic people from each of the priority groups within the datasets. When there are fewer than 10 respondents within a dataset, these data have not been analysed as the number is deemed too small to draw generalisable conclusions for the priority group. When there are fewer than 50 respondents from a particular priority group within a dataset, we recommend caution when interpreting the findings as this is a relatively small number of people so it may not be representative of the whole group.

Identification of priority groups: Where possible, the self-reported demographic information was used to identify respondents who were members of the priority groups. Where insufficient data are available to determine whether they were a member of a priority group, a note is made in the relevant priority group subsection.

For the “1,000 insights” community views survey, only data provided by Autistic people (and not other members of the autism community, such as professionals or parents) were included within this report. The reason for this is that demographics collected as part of this survey related to the person completing the questionnaire. These demographics were used to identify whether an Autistic respondent may be a member of each priority group. All data from the “Making therapy better” data were provided by Autistic people. Although parents completed the “Barriers to care” questionnaire, demographics for the Autistic child were used to identify whether the child was a member of each of the priority groups. Finally, for the Autism Connect helpline dataset, the focus was on the information pertaining to the Autistic person at the centre of the query, rather than necessarily on the person making the contact. As such, it is unknown how many of the people contacting Autism Connect were Autistic themselves, or how many were making contact on behalf of an Autistic person (e.g., parents/carers).

Autistic women and girls: For the “1,000 insights” community views, “Making therapy better” and “Barriers to care” surveys, this was based upon the gender of the Autistic person as described by the person completing the survey. For the Autism Connect dataset, the contact was specified as relating to an Autistic female, based on contact notes.

LGBTIQIA+: For the “1,000 insights” community views survey, respondents were asked if they identified as LGBTIQIA+. For the “Making therapy better” and “Barriers to care” surveys, LGBTIQIA+ identity data was not available. For the Autism Connect dataset, this included contacts related to Autistic individuals who identified with at least one of the LGBTIQIA+ identities, as recorded in the contact notes.

Regional, rural and remote: For the “1,000 insights” community views survey, postcode data provided by respondents was coded using delivery classifications from Australia Post and The Department of Agriculture, Fisheries and Forestry. Due to the classification systems used, rural, regional and remote areas were combined into one category. This broader grouping provided sufficient numbers of respondents to report on, enabling comparisons to be drawn to the overall sample of Autistic respondents, the majority of whom reported living in metropolitan regions. Postcode or geographical location data was not available for the “Barriers to care” or “Making therapy better” surveys. In the Autism Connect dataset, contacts were categorised as living in regional, rural or remote areas if these specific terms (regional, rural or remote) were used in the contact notes.

Low socio-economic status: For the “1,000 insights” community views survey, Autistic people with low socio-economic status consisted of those who self-rated themselves as being “poor” or “very poor” in response to the question “Given your current needs and financial responsibilities, would you say that you and your family are...”. For the “Barriers to care” questionnaire, respondents who stated their family income (pre-tax) was below \$45,000 were classified as low-socio economic status. Data on socio-economic position was not available for the “Making therapy better” or Autism Connect datasets.

Culturally and linguistically diverse: As per the Australian Bureau of Statistics (ABS) definition, this included people of non-English speaking background as well as people born outside Australia or whose parent was born overseas but whose first language is English. For the “1,000 insights” community views survey, respondents were asked if they identified CALD in the demographics section. For the “Making therapy better” and “Barriers to care” data, this was based upon each person’s answers to questions about ethnicity and place of birth. For the Autism Connect dataset, CALD status was determined from contact notes, for example if they explicitly indicated that the contact was about an Autistic person who was CALD, a migrant, or indicated English was not their primary language.

First Nations: For the “1,000 insights” community views surveys and “Making therapy better” surveys, respondents were asked if they identified as Aboriginal or Torres Strait Islander. For the “Barriers to care” survey, respondents were identified as First Nations through their response to the ethnicity question. In the Autism Connect dataset, contacts were identified as relating to an Autistic First Nations person only when this was explicitly stated in the contact notes.

High or complex disability needs: The definition for this was based upon what was provided in the documentation from the Department of Health and Aged Care and Roadmap Working Group, i.e. those who have high communication needs, high behaviour support needs, people in residential settings, people with intellectual disability or non-speaking Autistic people. For the “1,000 insights” community views survey, respondents were defined as having high or complex disability needs if they ticked the box which asked them if they identify as full-time or part-time users of AAC, as non-speaking, as having an intellectual disability, and/or as living in out-of-home care or supported accommodation. In the “Barriers to care” survey, Autistic children were identified as having high or complex disability needs if parents mentioned relevant co-occurring conditions, such as intellectual disability, in response to the question “Does your child have any co-occurring disability/condition in addition to autism?”. For the “Making therapy better” questionnaire, data on high or complex disability needs was not available. For the Autism Connect dataset, notes from the contact were used to identify those who met the Department of Health and Aged Care provided criteria for high or complex disability needs provided above.

Table 3-1: Data availability for Autistic people identifying within each priority group across physical health datasets

Dataset	Women and girls	LGBTIQ+	Regional, rural, and remote	Low socio-economic background	Culturally and linguistically diverse	First Nations	High or complex disability needs
“1,000 insights” community views survey (<i>n</i> = 253)	166	90	49	32	19	5	26
Autism Connect contacts (<i>n</i> = 292)	91	21	6	n/s	3	3	28
“Barriers to care” questionnaire (<i>N</i> = 107)	33	n/s	n/s	19	7	6	34
Subtotal	290	111	55	51	29	14	88

Table 3-2: Data availability for Autistic people identifying within each priority group across mental health datasets

Dataset	Women and girls	LGBTIQ+	Regional, rural, and remote	Low socio-economic background	Culturally and linguistically diverse	First Nations	High or complex disability needs
“1,000 insights” community views survey (<i>n</i> = 253)	168	87	55	32	19	5	58
Autism Connect contacts (<i>n</i> = 1514)	532	123	17	3	12	12	65
“Making therapy better” (<i>N</i> = 130)	114*	10	n/s	n/s	22	2	n/s
Subtotal	814	220	72	35	53	19	123

*As this represents 88% of the sample of this dataset, it is not meaningful to compare Autistic women and girls to the full sample, as it is very unlikely that differences will be found.

n/s = not stated; information on the demographics required to identify members of this priority group were not reported in the dataset.

2.5 Interpretation of data

Differences in experiences specific to a priority group: To identify substantial differences in the experiences of each priority group compared to the entire sample of Autistic people in the dataset, the difference in percentages and scores was explored. A “substantial difference” between the priority group and the entire sample of Autistic people was defined by a difference of 5% or greater (for contacts to Autism Connect and for reported topics within the “1,000 insights” community views survey). For the “Barriers to care” questionnaire and “Making therapy better” questionnaire scores, a substantial difference in scores was deemed to be 0.25 or greater.

Commonalities across sectors: To further enhance understanding of the experiences for each priority group, commonalities in the challenges experienced across both the physical health care and mental health care sectors were identified. That is, the data were examined to identify where comparable barriers or problems were experienced in both the mental health care sector and the physical health care sector. All data reported in the tables throughout this report were consulted to identify areas of overlap across both sectors.

3. What we found

3.1 Autistic women and girls

3.1.1 Physical health services

3.1.1.1 The “1,000 insights” community views survey physical health services

A total of 166 Autistic women answered at least one of the four open-ended questions on physical health services. These questions were:

- What are three problems that Autistic people experience when accessing, or trying to access, physical health services?
- What do you think is causing these problems?
- What do you think could prevent or reduce these problems?
- What is working well, or has worked well, for Autistic people in relation to physical health care services?

The ten most frequently reported responses to each of the questions are reported within this section. The tables include the proportion of Autistic women who provided a response that was coded into this category (with examples of the responses coded into this category) alongside the proportion of all Autistic people who provided a response that was coded into this category. Where there was a difference of 5% or more between the Autistic women and all Autistic respondents, the percentage difference is highlighted with bold and underlined text in the tables.

3.1.1.1.1 Problems experienced by Autistic women in relation to physical health services

A total of 163 Autistic women opted to answer this open-ended question in relation to physical health services. Table 4 ranks the 10 problems that Autistic women most frequently reported experiencing in relation to physical health services (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 4: Most frequently reported problems experienced by Autistic people in relation to physical health services, as reported by Autistic women

Rank	Problems experienced by Autistic people in relation to physical health services	% who stated this answer		
		Autistic women <i>n</i> = 163	Entire Autistic sample <i>n</i> = 253	% difference
1	Physical health care providers dismissing or not believing the reports of Autistic people or their family members (including not believing a person is Autistic) (e.g., dismissing symptoms or requests)	26%	26%	0%
2	Staff in health care settings (providers and administrative staff) have a poor understanding or knowledge of autism, how it presents in different people or contexts, and how it impacts the experience of health care settings (e.g., outdated knowledge of autism; lack of knowledge of how autism impacts the experience of health care settings)	21%	23%	-2%
3=	Differences or difficulties with communication, including Autistic people experiencing challenges with describing their experiences, having to frequently repeat information to providers, and physical health providers not presenting information in a way that is accessible to Autistic people (e.g., difficulties or fears associated with articulating needs or feelings)	20%	17%	3%
3=	The sensory elements of physical health services or settings (including waiting rooms and emergency departments) are not supportive for Autistic people, sometimes leading to sensory overwhelm (e.g., crowded, bright and noisy waiting rooms)	20%	19%	1%

Rank	Problems experienced by Autistic people in relation to physical health services	% who stated this answer		
		Autistic women <i>n</i> = 163	Entire Autistic sample <i>n</i> = 253	% difference
5	Health professionals' reluctance to adapt practices or provide accommodations/supports for Autistic individuals (e.g., inflexibility, one-size-fits-all, lack of neurodiversity-affirming care)	17%	17%	0%
6	Lack of knowledge on atypical presentations (including pain and masking) and treatment of health problems in Autistic people (e.g., lack of understanding about the diversity of sensory responses, presentation of characteristics in Autistic women and girls, and mental health needs of Autistic people)	16%	15%	1%
7=	Long waiting lists to access physical health services (e.g., long waiting time to access diagnostic, generalised, and specialised services)	15%	13%	2%
7=	Services are too expensive to access (e.g., challenges accessing NDIS funding, insufficient Medicare rebates)	15%	13%	2%
9=	Concerns about professional's therapeutic skills (e.g., lack of patience, empathy, care or understanding; mistreatment)	13%	16%	-3%
9=	Adjustments or accommodations not offered, or system not taking into account needs or preferences of Autistic people (e.g., appointments or therapies not autism-friendly; options for appointments [telehealth or in person]; and the process of arranging appointments or communicating with staff outside of appointments)	13%	15%	-2%

3.1.1.1.2 Factors causing the problems experienced by Autistic women in relation to physical health services

A total of 144 Autistic women opted to answer this open-ended question on physical health services.

Table 5 ranks the nine most commonly reported factors that Autistic women felt were causing the problems that Autistic people experience in relation to physical health services reported above. To ensure that the data was representative of the priority group, only those factors that were endorsed by 5% or more of the priority group are highlighted here. As such, on this occasion, only nine factors are reported.

Table 5: Most frequently reported causes of the problems experienced by Autistic people in relation to physical health services, as reported by Autistic women

Rank	Causes of the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic women <i>n</i> = 144	Entire Autistic sample <i>n</i> = 216	% difference
1	Staff in health care settings (including administrative settings) have a lack of knowledge or understanding of autism/neurodiversity, diversity of presentations, and how autism/neurodivergence may impact physical health needs or symptoms, such as pain (e.g.. lack of understanding individual needs; lack of understanding of autism; outdated knowledge)	34%	32%	2%
2	Lack of funding for autism education, training, and upskilling of physical health care professionals (e.g.. lack of training within undergraduate and postgraduate level; insufficient ongoing professional development and Autistic-led training)	31%	26%	5%
3	Health care professionals demonstrating a lack of understanding, empathy, patience, care, and acceptance for Autistic people (e.g.. professionals showing discrimination and stereotyping of autism)	15%	13%	2%
4	Insufficient number of available health care professionals (e.g.. lack of professionals entering the field; lack of staff retention and incentives; a lack of university placements to train new professionals)	12%	10%	2%

Rank	Causes of the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic women <i>n</i> = 144	Entire Autistic sample <i>n</i> = 216	% difference
5	Neurotypical/majority needs prioritised, ableism, and lack of neurodiversity-affirming practice (e.g.. services are not designed to be inclusive of Autistic people; there is an emphasis on the needs of the practitioner and non-Autistic clients)	10%	13%	-3%
6=	A system with overwhelmed and overworked staff, time pressures, and insufficient resources (e.g.. being rushed; no time for extra accommodations)	8%	7%	1%
6=	Lack of government support and guidance (e.g.. a lack of autism-specific research; lack of guidelines/policy; increased red tape and bureaucracy)	8%	10%	2%
8=	Health professionals' reluctance to adapt practices or provide accommodations/supports for Autistic individuals' or to see Autistic clients (e.g.. inflexibility; refusal to see Autistic clients)	7%	7%	0%
8=	Lack of individual supports and accommodations (e.g.. lack of knowledge of accommodations)	7%	7%	0%

3.1.1.1.3 Factors that could prevent or reduce the problems experienced by Autistic women in relation to physical health services

A total of 140 Autistic women opted to answer this open-ended question on physical health services. Table 6 ranks the 10 most commonly reported factors that Autistic women reported could prevent or reduce the problems that Autistic people experience in relation to accessing physical health services reported above.

Table 6: Most frequently reported factors that could prevent or reduce the problems experienced by Autistic people in relation to physical health services, as reported by Autistic women

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic women <i>n</i> = 140	Entire Autistic sample <i>n</i> = 210	% difference
1	Increase (access to) education, training, and upskilling programs for health care professionals and administrative staff about autism, characteristics, and health impacts (e.g., mandatory onboarding; Autistic informed/delivered training; and university level training)	55%	51%	4%
2	Increase access and use of physical health care services for Autistic people and their families through the provision of accommodations, flexible access options, and supports (e.g., increased flexibility; and increased access to supports)	17%	14%	3%
3=	Increase communication options to improve access to health care and access to information about health care (e.g., web-based booking systems; text-based communication; opting in or out of telehealth [i.e., not assuming it is preferred or unpreferred])	16%	17%	-1%
3=	Increase funding/resources and/or affordability of health services across the lifespan (e.g., increasing access to funding; increasing bulk-billing services; reviewing funding systems such as NDIS)	16%	17%	-1%
5	Increase the number of health care professionals and health services available (e.g., incentives to increase rural/regional service; broadening scope of practice for health professionals)	15%	13%	2%
6=	Government reform, support, and guidance (e.g., investment in research and services; guidelines, policy and regulations)	11%	14%	-3%

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic women <i>n</i> = 140	Entire Autistic sample <i>n</i> = 210	% difference
6=	Create sensory-friendly physical health services or settings, including training to inform health care professionals of how overwhelming these environments can be for Autistic people and the impact this may have on their appointment (e.g., create sensory-friendly waiting rooms and emergency departments)	11%	11%	0%
8=	Enhance the therapeutic skills and awareness of health care professionals to support their work with Autistic clients (e.g., acceptance; showing empathy and patience)	10%	12%	-2%
8=	Listen, validate and take concerns of Autistic individuals and their families/carers seriously (e.g., asking questions, working in partnership with clients)	10%	9%	1%
10	Actively employ, consult, and collaborate with neurodivergent practitioners, support workers, advocates, and those in leadership/decision-making roles (e.g., consult with Autistic people when designing or developing services; services actively employing neurodivergent practitioners, support workers, advocates)	9%	10%	-1%

3.1.1.1.4 Factors that are working well, or have worked well, for Autistic women in relation to physical health services

Overall, 109 Autistic women replied to this open-ended question. Table 7 ranks the 11 most commonly reported factors that Autistic women reported to be working well, or that have worked well, for Autistic people in relation to physical health services.

Table 7: Most frequently reported factors that are working well, or have worked well, for Autistic people in relation to physical health services, as reported by Autistic women

Rank	What is working well, or has worked well, in relation to Autistic people's experiences with physical health services	% who stated this answer		
		Autistic women <i>n</i> = 109	Entire Autistic sample <i>n</i> = 161	% difference
1	Nothing/not a lot	22%	28%	-6%
2	When you find the right physical health provider for you, who was often described as knowledgeable about autism, understanding, caring, patient, and non-judgemental (e.g., understands autism and neurodiversity; compassionate; gentle; empathetic)	17%	21%	-4%
3	When there are increased communication options to improve access to, and information about, health care (e.g., web-based booking systems; option of telehealth; non-verbal communication options)	13%	12%	1%
4=	When health care providers proactively ask about and provide alternative/flexible access, accommodations, and/or support for Autistic individuals (e.g., longer appointments; more flexibility with appointments; support people attending; home visits)	11%	9%	2%
4=	When NDIS plans and funding are approved for health supports (e.g., helpful NDIS coordinators can improve access to services; reduces financial burden on families)	11%	9%	2%
6	When there is increased access to autism-informed health professionals and services (e.g., Autistic-led services; services that have expertise in autism)	9%	8%	1%

Rank	What is working well, or has worked well, in relation to Autistic people's experiences with physical health services	% who stated this answer		
		Autistic women <i>n</i> = 109	Entire Autistic sample <i>n</i> = 161	% difference
7	When providers ask questions and listen to Autistic people and/or their family members, and include Autistic individuals and their families in health care decisions (e.g., open communication; respectful practice; seeking consent, preferences, and opinions)	8%	8%	0%
8	Recent shift towards neuro-affirming and strength-based practice (e.g., focusing on the social model of health)	7%	7%	0%
9=	Health care providers having an awareness and knowledge of autism, the characteristics of autism (including sensory needs), and different presentations (including the presentation of autism in women or girls) (e.g., autism trained and experienced health care professionals; awareness of diversity in pain presentation)	6%	6%	0%
9=	When there is continuity of care and continuity of information across providers (e.g., collaborative health teams; building relationships; individual care plans; accessible health information; health passports)	6%	6%	0%
9=	When health care services are affordable and there is access to funding (beyond NDIS) (e.g., Medicare rebates; bulk billing; and Health Care cards)	6%	6%	0%

3.1.1.2 Autism Connect dataset: Contacts relating to physical health

A total of 292 contacts to Autism Connect referred to physical health-related issues, 91 of which were specifically in relation to Autistic women or girls. The most frequent physical health care issues that the contact related to are reported within this section. Table 8 ranks the most frequent physical health-related issues that person contacted Autism Connect to discuss. The data are ranked from most frequently reported to least frequently reported issues. Where there was a difference of 5% or more between contacts related to Autistic women and girls and all Autistic respondents, the percentage difference is highlighted with bold and underlined text in the tables.

Table 8: Most frequent physical health-related issues raised in contacts to Autism Connect by, or related to, Autistic women or girls

Topic (contacts)	Physical health issue raised	% contacts for physical health-related issues		
		For Autistic women and girls <i>n</i> = 91	All contacts <i>n</i> = 292	% difference between groups
Finding a health care provider (<i>n</i> = 73)	GP	27.5%	23.3%	4.2%
	Other physical health professionals	19.8%	21.2%	-1.4%
	Paediatrician	14.3%	14.7%	-0.4%
	Nutrition or dietetics	13.2%	19.2%	<u>-6%</u>
	Occupational therapist (physical health reasons)	4.4%	1.0%	3.4%
	Support worker (physical health reasons)	1.1%	1.0%	0.1%
Funding information (<i>n</i> = 3)	NDIS funding (physical health reasons)	2.2%	1.0%	1.2%
	Non-NDIS funding (physical health reasons)	1.1%	1.0%	0.1%
Advice (<i>n</i> = 15)	General physical health advice	16.4%	14.0%	2.4%

3.1.1.3 “Barriers to care” questionnaire

A total of 33 parents of Autistic girls responded to the questionnaire that asked them to rank predetermined statements relating to barriers to accessing acute physical health care. The five barriers on the “Barriers to care” questionnaire with the highest mean scores (i.e., happen most frequently) for Autistic girls are represented in Table 9. Where there was a difference of 0.25 or more between parent ratings for Autistic girls and all Autistic children, the score difference is highlighted with bold and underlined text in the tables.

Table 9: Five highest scoring barriers to acute physical health care on the “Barriers to care” questionnaire, as reported by parents of Autistic girls

“Barriers to care” questionnaire Question	Mean (SD) Autistic girls <i>n</i> = 33	Mean (SD) entire sample <i>N</i> = 107	Score difference for Autistic girls
Worrying that doctors and nurses will not do what is right for your Autistic child	3.73 (1.38)	3.64 (1.34)	0.10
Having to wait too long in the waiting room	3.67 (1.43)	3.96 (1.30)	<u>-0.29</u>
Getting hold of the doctor	3.52 (1.54)	3.86 (1.32)	<u>-0.34</u>
Getting a thorough examination	3.48 (1.40)	3.62 (1.33)	0.14
Lack of communication between different parts of the health care system	3.48 (1.48)	3.34 (1.41)	0.14

The five barriers on the “Barriers to care” questionnaire with the lowest mean scores (i.e., happen least frequently) for Autistic girls are represented in Table 10.

Table 10: Five lowest scoring barriers to acute physical health care on the “Barriers to care” questionnaire, as reported by parents of Autistic girls

“Barriers to care” questionnaire Question	Mean (SD) Autistic girls <i>n</i> = 33	Mean (SD) entire sample <i>N</i> = 107	Score difference for Autistic girls
Doctors or nurses not fluent in your native language	1.45 (1.03)	1.41 (.98)	0.04
Doctors not believing in home or traditional remedies	1.58 (1.20)	1.70 (1.26)	-0.12
Understanding doctors’ orders	1.64 (.96)	1.54 (.91)	0.10
Getting enough help with paperwork or forms	1.82 (1.36)	1.70 (1.19)	0.12
Being judged on your appearance, your ancestry, or your accent	1.91 (1.36)	1.93 (1.33)	-0.02

3.1.2 Mental health services

3.1.2.1 The “1,000 insights” community views survey mental health services

A total of 168 Autistic women answered at least one of the four open-ended questions on mental health services. These four questions were:

- What are three problems that Autistic people experience when using, or trying to access, mental health services?
- What do you think is causing these problems?
- What do you think could prevent or reduce these problems?
- What is working well, or has worked well, for Autistic people when using or trying to access mental health services?

The most frequently reported responses to each of the questions are reported within this section. The tables include the proportion of Autistic women who provided a response that was coded into this category (with examples of the responses coded into this category), alongside the proportion of all Autistic people who provided a response that was coded into this category. Where there was a difference of 5% or more between the Autistic women and all Autistic people, the percentage difference is highlighted with bold and underlined text in the tables.

3.1.2.1.1 Problems experienced by Autistic women in relation to mental health services

A total of 166 Autistic women opted to answer this open-ended question in relation to mental health services. Table 11 ranks the 11 problems that Autistic women most frequently reported Autistic people experiencing in relation to mental health services (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 11: Most frequently reported problems experienced by Autistic people in relation to mental health services, as reported by Autistic women

Rank	Problems experienced by Autistic people in relation to mental health services	% who stated this answer		
		Autistic women <i>n</i> = 166	Entire Autistic sample <i>n</i> = 250	% difference
1	Prohibitive cost (e.g., very expensive; services able to charge too much)	29%	28%	1%
2	Lack of knowledge or understanding of autism/neurodiversity, its presentation, and its impact across the lifespan (e.g., lack of knowledge about autism in females; lack of understanding of lived experience)	25%	28%	-3%
3	Long or closed waitlists (e.g. long waiting time to access diagnostic services, psychologists, and psychiatrists; waiting lists exacerbate issues)	20%	19%	1%
4	Insufficient availability/access of relevant, skilled mental health worker (e.g., lack of providers who can do assessments; challenges finding neurodivergent therapist)	19%	18%	1%
5=	Insufficient availability/access of appropriate services (e.g., lack of services specialising in autism; long distance to travel)	14%	17%	-3%
5=	Misdiagnosis of autism and/or co-occurring conditions (e.g., misdiagnosing autism as, for example, a personality disorder; diagnostic overshadowing)	14%	12%	2%
7	Strategies not tailored for the individual client or neurodivergent people (e.g., not tailored for individual needs or preferred goals; neurotypical strategies do not always work for Autistic people)	11%	10%	1%

Rank	Problems experienced by Autistic people in relation to mental health services	% who stated this answer		
		Autistic women <i>n</i> = 166	Entire Autistic sample <i>n</i> = 250	% difference
8=	Professionals may make assumptions or have pre-conceived ideas of autism, holding a deficit-based view (e.g., stereotyping; behaviours viewed as attention seeking)	10%	10%	0%
8=	Trivialising or not believing someone's autism diagnosis or their lived experience (e.g., not believing someone's experience)	10%	10%	0%
10=	Concerns about a professional's therapeutic skills (e.g., lack of genuine care; discriminatory towards Autistic people)	8%	10%	-2%
10=	Lack of neuro-affirming practice (e.g., encouraged to function in neurotypical way; trained to mask)	8%	6%	2%

3.1.2.1.2 Factors causing the problems experienced by Autistic people in relation to mental health

A total of 142 Autistic women opted to answer the open-ended question on mental health services. Table 12 ranks the most commonly reported factors that Autistic women respondents felt were causing the problems that Autistic people experience in relation to mental health services reported above. The data are ranked from most frequently reported to least frequently reported.

Table 12: Most frequently reported causes of the problems experienced by Autistic people in relation to mental health services, as reported by Autistic women

Rank	Causes of the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic women <i>n</i> = 142	Entire Autistic sample <i>n</i> = 213	% difference
1	Lack of knowledge or understanding of autism and neurodivergent conditions, its presentation, and its impact (e.g., lack of understanding the heterogeneous presentation of autism; lack of understanding of stresses associated with autism)	34%	28%	<u>6%</u>
2	Lack of, or poor quality of, training for mental health professionals (e.g., poor training; lack of training in diagnosing and treating autism appropriately)	27%	27%	0%
3	Insufficient funding (generally) (e.g., lack of funding; funding shortfall)	15%	15%	0%
4=	Concern about therapeutic skills and/or attitude (e.g., lack of respect; ableism; not allowing time to develop relationship; ignorance)	13%	17%	-4%
4=	Insufficient number of professionals with an interest/expertise in autism (e.g., lack of qualified people specialising in autism; lack of specialists in rural areas)	13%	12%	1%
6=	Impact of decisions made by the government (e.g., government policies; government cuts; poor management of mental health services)	10%	10%	0%

Rank	Causes of the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic women <i>n</i> = 142	Entire Autistic sample <i>n</i> = 213	% difference
6=	Overwhelmed system/professionals with insufficient resources (e.g., lack of resources; overwhelmed staff; time pressure)	10%	7%	3%
8	Strategies and practices considered insufficient, inappropriate, or poor quality (e.g., lack of awareness of how to modify practices; neuro-normative concepts of well-being applied to Autistic people)	9%	9%	0%
9=	Lack of research and Autistic-informed care in mental health services (e.g., evidence base is needed for women and girls; lack of co-designing services with Autistic people)	8%	8%	0%
9=	Challenges with Medicare support (e.g., no funding for autism assessment/therapy for people older than 15 years; out of pocket cost too high)	8%	8%	0%
9=	The system is challenging and is not designed to support the access/use of Autistic people (e.g., inflexible; access needs are not enquired about)	8%	6%	2%

3.1.2.1.3 Factors that could prevent or reduce the problems experienced by Autistic women in relation to mental health services

A total of 134 Autistic women opted to answer this open-ended question on mental health services. Table 13 ranks the 10 most commonly reported factors that Autistic women reported could prevent or reduce the problems that Autistic people experience in relation to accessing mental health services reported above (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 13: Most frequently reported factors that could prevent or reduce the problems experienced by Autistic people in relation to mental health services, as reported by Autistic women

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic women <i>n</i> = 134	Entire Autistic sample <i>n</i> = 199	% difference
1	Increase (access to) training for people working as mental health professionals to enhance their understanding of autism (and other neurodivergence), including training from Autistic people with lived experience (e.g., mandatory, regular training; Autistic informed/delivered training)	46%	46%	0%
2	More mental health professionals, including those specialising in autism, and those who are Autistic/neurodivergent themselves (e.g., more doctors; more psychologists; create new roles and professions to support Autistic people; incentives for experts; alternative qualification pathways)	20%	19%	1%
3	Increase funding and/or affordability of mental health services across the lifespan (e.g., government funded functional capacity assessment; price caps and/or rebates)	19%	19%	0%
4=	Enhance the therapeutic skills and awareness of mental health professionals to support their work with Autistic clients (e.g., listen to [and believe] the client to identify challenges; account for possible challenges in identifying emotions or forming trust)	10%	11%	-1%
4=	Improve access to, and quality of, services (e.g., reduce the red tape; consideration of access for regional and rural areas; services for people with complex needs)	10%	9%	1%

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic women <i>n</i> = 134	Entire Autistic sample <i>n</i> = 199	% difference
4=	Make access and use of services easier and more autism-friendly (e.g., alternative methods to book appointments, increased flexibility of appointments; environment)	10%	10%	0%
7=	Enhance the quality of university education and number of places available (e.g., do not phase out psychology general registration pathway; provide education on neurodiversity-affirming practice; include information on co-occurring intellectual disability and other co-occurring conditions)	9%	9%	0%
7=	Implement Medicare-specific improvements for increasing affordability of mental health care (e.g., allow provisional psychologists to work under Medicare; Medicare funding for mental health)	9%	9%	0%
9=	Facilitate changes to practice to focus on strengths, neurodiversity-affirming care, and skills relevant to supporting Autistic people (e.g., use social model rather than medical model; neurodiversity-affirming practice)	8%	10%	-2%
9=	Implement NDIS specific improvements for funding access (e.g., more inclusive funding; automatic access to NDIS for Autistic people)	8%	7%	1%

3.1.2.1.4 Factors that are working well, or have worked well, for Autistic women in relation to mental health services

A total of 103 Autistic women opted to answer this open-ended question on mental health services. Table 14 ranks the 10 most commonly reported factors that Autistic women reported to be working well, or that have worked well, for Autistic people in relation to mental health (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 14: Most frequently reported factors that are working well, or have worked well, for Autistic people in relation to mental health services, as reported by Autistic women

Rank	What is working well, or has worked well, in relation to Autistic people’s experiences with mental health services	% who stated this answer		
		Autistic women <i>n</i> = 103	Entire Autistic sample <i>n</i> = 155	% difference
1	Nothing/not a lot	23%	25%	-2%
2	When you find the right mental health professional for you, who is often knowledgeable/experienced about autism and its associated needs (e.g., understands autism and neurodiversity; experience working with Autistic people)	19%	18%	1%
3	When NDIS funding has been provided to support needs (e.g., NDIS can reduce mental health challenges when all needs are covered; supportive NDIS plan manager)	14%	13%	1%
4	When alternative/flexible access are available (inc. making appointment and practice) (e.g., online chat services; alternative booking options such as leaving voice message or online portal)	12%	13%	-1%
5=	When a professional has lived experience (e.g., are Autistic/neurodivergent, or have Autistic family members)	11%	10%	1%
5=	The recent shift towards neurodiversity-affirming and strengths-based practice, rather than relying on medical model (e.g., focus on the strengths of a person rather than the challenges)	11%	9%	2%

Rank	What is working well, or has worked well, in relation to Autistic people’s experiences with mental health services	% who stated this answer		
		Autistic women <i>n</i> = 103	Entire Autistic sample <i>n</i> = 155	% difference
7	Accommodations to support Autistic people (e.g., informing clients of the steps; providing processing time; writing summaries of key ideas; more frequent shorter sessions; autism friendly sensory environments)	9%	6%	3%
8	When a professional has good therapeutic skills (e.g., compassionate, flexible, listens, patient, speaking calmly)	7%	6%	1%
9=	Affordable health care when it is accessible (e.g., cheap or bulk billed services with health care card; professions registered within “better access to mental health”; twenty extra sessions during COVID)	6%	6%	1%
9=	A range of different approaches and modifications highlighting that no single approach is suitable for everyone (e.g., trauma-informed; assistance animals; art therapy; social skills sessions; psychotherapy; group sessions)	5%	6%	-1%

3.1.2.1.5 Autism Connect dataset: Contacts relating to mental health

A total of 532 of the contacts to Autism Connect referred to mental health issues, specifically relating to Autistic women or girls. The most frequent issues that the contact related to in terms of mental health are reported within this section. Table 15 ranks the most frequent mental health-related issues that the person contacted Autism Connect discuss. The data are ranked from most frequently reported to least frequently reported issues.

Table 15: Most frequent mental health-related issues raised in contacts to Autism Connect by, or related to, Autistic women or girls

Topic (contacts)	Mental health issue raised	% contacts for mental health-related issues		
		For Autistic women and girls <i>n</i> = 532	All contacts <i>n</i> = 1,491	% difference between groups
Seeking therapist (<i>n</i> = 449)	Psychologist	55.1%	52.2%	-0.1%
	Psychiatrist	11.3%	12.4%	-1.1%
	Other or unspecified mental health support	4.1%	5.6%	-1.5%
	General therapists (mental health reasons)	3.2%	3.7%	-0.5%
	Counsellor	3.2%	3.7%	0.1%
	Seeking autism diagnosis prompted by mental health challenges	3.0%	1.9%	1.1%
	Occupational therapist (mental health reasons)	1.3%	1.2%	0.1%
	Unspecified but for a specific goal or support	0.9%	0.8%	0.1%
	Support worker (mental health reasons)	0.6%	0.3%	0.3%
	Animal therapy for mental health	0.6%	0.3%	0.3%
	Social work relating to mental health	0.2%	0.1%	0.1%

Topic (contacts)	Mental health issue raised	% contacts for mental health-related issues		
		For Autistic women and girls <i>n</i> = 532	All contacts <i>n</i> = 1,491	% difference between groups
Funding information (<i>n</i> = 4)	Non-NDIS funding (mental health reasons)	0.8%	0.1%	0.7%
Advice (<i>n</i> = 84)	Mental health advice	10.2%	10.3%	-0.1%
	Work or employment impacting mental health	2.8%	2.0%	0.8%
	Education impacting mental health	2.1%	1.7%	0.4%
	Family issues relating to mental health	0.4%	0.5%	-0.1%
	Relationships impacting mental health	0.2%	0.4%	-0.2%

3.1.2.3 Making therapy better questionnaire

A total of 114 Autistic women responded to the questionnaire about ways of making mental health supports/therapy better for Autistic people. However, this means that nearly all the sample were women (only *n* = 16 did not identify as women), so comparisons to the entire Autistic sample are not meaningful as they are unlikely to identify many or any differences. Further, in-depth work is needed with Autistic women and girls to address this area.

3.1.3 Summary of findings for Autistic women and girls

3.1.3.1 Summary of differences noted in the data for Autistic women and girls as compared to the data for the entire Autistic sample

The focus of this section is on any items that differed within datasets provided by, or in relation to, Autistic girls and women and the data for the entire Autistic sample. A general summary of the issues with physical health and mental health services raised by, or in relation to, Autistic women and girls is provided in Section 3.1.3.2.

Across the datasets for both the physical and mental health service domains, six areas (see Figure 1) met the predefined criteria for a substantial difference (defined as a 5% or greater difference on the 1,000 insights community views survey or Autism Connect contacts, or .25 points or greater difference between groups on the “Barriers to care” questionnaire). A notable finding from Figure 1 is that Autistic women and girls indicate a need for health care professionals, both in physical and mental health, to have enhanced training and knowledge in autism and other neurodivergent conditions.

Figure 1: Summary of substantial differences for Autistic women and girls in existing datasets for physical and mental health service experiences

In relation to physical and mental health care services, Autistic women and girls were more likely to...

- ▲ Attribute problems within the mental health system to the service providers' lack of knowledge about autism (+6% difference; “1,000 insights” survey)
- ▲ Highlight that there is insufficient autism education, training and upskilling of physical health care professionals (+5% difference; “1,000 insights” survey).

In relation to physical and mental health care services, Autistic women and girls, or their parent/caregivers, were less likely to...

- ▼ Make contact with Autism Connect, or have contact made about them, for assistance with finding information on nutrition or dietetics (-6%)
 - ▼ Report that nothing has worked well for them in the physical health care system (-6%; “1,000 insights” survey)
 - ▼ Rate waiting too long in the waiting room (-0.29; “Barriers to care” questionnaire)
 - ▼ Rate challenges getting hold of the doctor (-0.34; “Barriers to care” questionnaire) as important barriers although they are still reported as significant barriers.
-

3.1.3.2 Summary of issues or experiences with physical and/or mental health services for Autistic women and girls as reported in the four datasets

The issues and experiences within physical health and mental health services have been described individually above. This section focuses on highlighting areas raised for Autistic women and girls across both physical health and mental health services datasets.

The data reflect information gathered in multiple ways: (a) open text answers to a survey, (b) rating level of agreement on a rating scale, and (c) contact with Autism Connect helpline. Despite these differences in how the data were obtained, commonalities were identified across the responses provided in the physical and mental health service domains.

Perspectives common across physical and mental health service experiences: Commonalities in the problems identified by Autistic women and girls across the physical and mental health service domains in the “1,000 insights” community views survey include:

- (a) large or prohibitive **costs** associated with the service,
- (b) a **limited knowledge** or understanding of autism held by professionals,
- (c) **long or closed waitlists** to access these services,
- (d) **professionals not believing the lived experience** of Autistic people,
- (e) **professionals not tailoring strategies** to be suitable for Autistic people,
- (f) Autistic people holding **concerns about the therapeutic skills** of professionals (e.g., exhibiting discriminatory behaviours or lack of empathy).

The challenge with finding a provider (who has availability and/or autism knowledge) is also reflected in the Autism Connect dataset, where the vast majority of contacts relating to both physical health care and mental health care were to find a health care practitioner.

The six themes reported above were echoed in both what Autistic women and girls perceive to be the causes of these problems, and in strategies that could be used to reduce them across both physical and mental health responses. Specifically, an increase in the availability (and accessibility) of **funding** was considered important across both domains, as was enhancing access to, and the quality of, autism **training** for people working within these service domains. In turn, this improved training could **increase the knowledge of professionals**, and their confidence or ability to select or **modify strategies** to better support Autistic women and girls, including the use of **neurodiversity-affirming** strategies. This increased knowledge could also enhance professionals’ **therapeutic skills**.

Finally, **flexibility, or a lack thereof**, was also frequently reported as either a cause of the problems experienced or a possible solution/facilitator. Autistic women and girls highlighted a need for flexibility in access to, and use within, physical and mental health care services including how appointments are made (e.g., online or via telephone), having longer therapy sessions (rather than shorter, which the “Making therapy better” questionnaire indicated can be less helpful), or being able to use alternative and augmented communication methods.

Commonalities across different domains and different data collection methods highlight the robust nature of these challenges experienced by Autistic women and girls. These commonalities provide ideal starting points for improvements to these service domains that could be beneficial for Autistic women and girls in Australia.

3.2 Autistic people who identify as LGBTIQ+

3.2.1 Physical health services

3.2.1.1 The “1,000 insights” community views survey physical health services

A total of 90 Autistic LGBTIQ+ people answered at least one of the four open-ended questions on physical health services. These questions were:

- What are three problems that Autistic people experience when accessing, or trying to access, physical health services?
- What do you think is causing these problems?
- What do you think could prevent or reduce these problems?
- What is working well, or has worked well, for Autistic people in relation to physical health care services?

The most frequently reported responses to each of the questions are reported within this section. The tables include the proportion of Autistic LGBTIQ+ people who provided a response that was coded into this category (with examples of the responses coded into this category) alongside the proportion of all Autistic people who provided a response that was coded into this category. Where there was a difference of 5% or more between Autistic LGBTIQ+ people and all Autistic respondents, the percentage difference is highlighted through bold and underlined text in the tables.

3.2.1.1.1 Problems experienced by Autistic LGBTIQ+ people in relation to physical health services

A total of 89 Autistic LGBTIQ+ people opted to answer this open-ended question in relation to physical health services. Table 16 ranks the 11 problems that Autistic LGBTIQ+ people most frequently reported Autistic people experiencing in relation to physical health services (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 16: Most frequently reported problems experienced by Autistic people in relation to physical health services, as reported by Autistic LGBTIQ+ people

Rank	Problems experienced by Autistic people in relation to physical health services	% who stated this answer		
		Autistic LGBTIQ+ people <i>n</i> = 89	Entire Autistic sample <i>n</i> = 253	% difference
1	Physical health care providers dismissing or not believing the reports of Autistic people or their family members (including not believing a person is Autistic) (e.g., dismissing symptoms or requests)	29%	26%	3%
2	Adjustments or accommodations not offered, or system not taking into account needs or preferences of Autistic people (e.g., appointments or therapies not autism-friendly; options for appointments [telehealth or in person]; and the process of arranging appointments or communicating with staff outside of appointments)	22%	15%	<u>7%</u>
3	Staff in health care settings (providers and administrative staff) have a poor understanding or knowledge of autism, how it presents in different people or contexts, and how it impacts the experience of health care settings (e.g., outdated knowledge of autism; lack of knowledge of how autism impacts the experience of health care settings)	21%	23%	-2%
4	Health professionals' reluctance to adapt practices or provide accommodations/supports for Autistic individuals (e.g., inflexibility, one-size-fits-all, lack of neurodiversity-affirming care)	18%	17%	1%
5	Lack of knowledge on atypical presentations (including pain and masking) and treatment of health problems in Autistic people (e.g., lack of understanding about the diversity of sensory responses, presentation of characteristics in Autistic women and girls, and mental health needs of Autistic people)	16%	15%	1%

Rank	Problems experienced by Autistic people in relation to physical health services	% who stated this answer		
		Autistic LGBTIQ+ people <i>n</i> = 89	Entire Autistic sample <i>n</i> = 253	% difference
6=	Concerns about professional's therapeutic skills (e.g., lack of patience, empathy, care or understanding; mistreatment)	15%	16%	-1%
6=	Services are too expensive to access (e.g., challenges accessing NDIS funding, insufficient Medicare rebates)	15%	13%	2%
6=	The sensory elements of physical health services or settings (including waiting rooms and emergency departments) are not supportive for Autistic people, sometimes leading to sensory overwhelm (e.g., crowded, bright and noisy waiting rooms)	15%	19%	-4%
9	Differences or difficulties with communication, including Autistic people experiencing challenges with describing their experiences, having to frequently repeat information to providers, and physical health providers not presenting information in a way that is accessible to Autistic people (e.g., difficulties or fears associated with articulating needs or feelings)	13%	17%	-4%
10=	Long waiting lists to access physical health services (e.g., long waiting time to access diagnostic, generalised, and specialised services)	12%	13%	-1%
10=	Difficulties with the process to access and physically attend health services (e.g., organising and understanding forms, service availability/options, paperwork and appointments; transport)	12%	12%	0%

3.2.1.1.2 Factors causing the problems experienced by Autistic LGBTQIA+ people in relation to physical health services

A total of 87 Autistic LGBTQIA+ people opted to answer this open-ended question on physical health services. Table 17 ranks the most commonly reported factors that Autistic LGBTQIA+ respondents felt were causing the problems that Autistic people experience in relation to physical health services reported above.

Table 17: Most frequently reported causes of the problems experienced by Autistic people in relation to physical health services, as reported by Autistic LGBTQIA+ people

Rank	Causes of the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic LGBTQIA+ people <i>n</i> = 87	Entire Autistic sample <i>n</i> = 216	% difference
1	Staff in health care settings (providers and administrative staff) have a poor understanding or knowledge of autism/ neurodiversity, diversity of presentations, and how autism/ neurodivergence may impact physical health needs, such as pain (e.g., lack of understanding individual needs; lack of understanding of autism; outdated knowledge)	29%	32%	-3%
2	Lack of funding for autism education, training, and upskilling of physical health care professionals (e.g., lack of training within undergraduate and postgraduate level; insufficient ongoing professional development and Autistic-led training)	20%	26%	<u>-6%</u>
3	Neurotypical/majority needs prioritised, ableism, and lack of neurodiversity-affirming practice (e.g., services are not designed to be inclusive of Autistic people; there is an emphasis on the needs of the practitioner and non-Autistic clients)	18%	13%	<u>5%</u>
4=	Dismissing or excluding an Autistic person or their family (e.g., lack of questioning; ignoring symptoms and health concerns)	13%	8%	<u>5%</u>
4=	Lack of funding/resources and/or difficulty accessing these supports (including the high costs of health care) (e.g., very expensive; funding shortfall; limited bulk-billing services)	13%	18%	<u>-5%</u>

Rank	Causes of the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic LGBTIQA+ people <i>n</i> = 87	Entire Autistic sample <i>n</i> = 216	% difference
6	Health professionals' reluctance to adapt practices or provide accommodations/supports for Autistic individuals' or to see Autistic clients (e.g., inflexibility; refusal to see Autistic clients)	11%	7%	4%
7	Health care professionals demonstrating a lack of understanding, empathy, patience, care, and acceptance for Autistic people (e.g., professionals showing discrimination and stereotyping of autism)	10%	13%	-3%
8	Communication, processing, and social interaction differences and/or difficulties (e.g., processing issues; having to repeat information)	8%	7%	1%
9	Insufficient number of professionals or services with an interest/expertise in autism (e.g., a lack of Autistic professionals or those with lived experience; a lack of specialists in rural areas)	7%	6%	1%

3.2.1.1.3 Factors that could prevent or reduce the problems experienced by Autistic LGBTIQ+ people in relation to physical health services

A total of 70 Autistic LGBTIQ+ people opted to answer this open-ended question on physical health services. Table 18 ranks the nine most commonly reported factors that Autistic LGBTIQ+ people reported could prevent or reduce the problems that Autistic people experience in relation to accessing physical health services reported above.

Table 18: Most frequently reported factors that could prevent or reduce the problems experienced by Autistic people in relation to physical health services, as reported by Autistic LGBTIQ+ people

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic LGBTIQ+ people <i>n</i> = 70	Entire Autistic sample <i>n</i> = 216	% difference
1	Increase (access to) education, training, and upskilling programs for health care professionals and administrative staff about autism, characteristics, and health impacts (e.g., mandatory onboarding; Autistic informed/delivered training; and university level training)	56%	51%	<u>5%</u>
2	Increase communication options to improve access to health care and access to information about health care (e.g., web-based booking systems; text-based communication; opting in or out of telehealth [i.e., not assuming it is preferred or unpreferred])	24%	17%	<u>7%</u>
3=	Enhance the therapeutic skills and awareness of health care professionals to support their work with Autistic clients (e.g., acceptance; showing empathy and patience)	16%	12%	4%
3=	Increase access and use of physical health care services for Autistic people and their families through the provision of accommodations, flexible access options, and supports (e.g., increased flexibility; and increased access to supports)	16%	14%	2%
5	Increase funding/resources and/or affordability of health services across the lifespan (e.g., increasing access to funding; increasing bulk-billing services; reviewing funding systems such as NDIS)	14%	17%	-3%

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic LGBTIQA+ people <i>n</i> = 70	Entire Autistic sample <i>n</i> = 216	% difference
6	Increase the number of health care professionals and health services available (e.g., incentives to increase rural/regional service; broadening scope of practice for health professionals)	11%	13%	-2%
7=	Government reform, support, and guidance (e.g., investment in research and services; guidelines, policy and regulations)	10%	14%	-4%
7=	Actively employ, consult, and collaborate with neurodivergent practitioners, support workers, advocates, and those in leadership/decision-making roles (e.g., consult with Autistic people when designing or developing services; services actively employing neurodivergent practitioners, support workers, advocates)	10%	10%	0%
7=	Create sensory-friendly physical health services or settings, including training to inform health care professionals of how overwhelming these environments can be for Autistic people and the impact this may have on their appointment (e.g., create sensory-friendly waiting rooms and emergency departments)	10%	11%	-1%

3.2.1.1.4 Factors that are working well, or have worked well, for Autistic LGBTIQ+ people in relation to physical health services

Overall, 47 Autistic LGBTIQ+ people replied to this open-ended question. Table 19 ranks the 10 most commonly reported factors that Autistic LGBTIQ+ people reported to be working well, or that have worked well, for Autistic people in relation to physical health services.

Table 19: Most frequently reported factors that are working well, or have worked well, for Autistic people in relation to physical health services, as reported by Autistic LGBTIQ+ people

Rank	What is working well, or has worked well, in relation to Autistic people's experiences with physical health services	% who stated this answer		
		Autistic LGBTIQ+ people <i>n</i> = 47	Entire Autistic sample <i>n</i> = 161	% difference
1	Nothing /not a lot	34%	28%	<u>6%</u>
2	When you find the right physical health provider for you, who was often described as knowledgeable about autism, understanding, caring, patient, and non- judgemental (e.g., compassionate; gentle; empathetic)	26%	21%	<u>5%</u>
3	When there are increased communication options to improve access to, and information about, health care (e.g., web-based booking systems; option of telehealth; non-verbal communication options)	13%	12%	1%
4	When health care providers proactively ask about and provide alternative/flexible access, accommodations, and/or support for Autistic individuals (e.g., longer appointments; more flexibility with appointments; support people attending; home visits)	11%	9%	2%
5=	When providers ask questions and listen to Autistic people and/or their family members, and include Autistic individuals and their families in health care decisions (e.g., open communication; respectful practice; seeking consent, preferences and opinions)	9%	8%	1%
5=	When there is continuity of care and continuity of information across providers (e.g., collaborative health teams; building relationships; individual care plans; accessible health information; health passports)	9%	6%	3%

Rank	What is working well, or has worked well, in relation to Autistic people's experiences with physical health services	% who stated this answer		
		Autistic LGBTIQA+ people <i>n</i> = 47	Entire Autistic sample <i>n</i> = 161	% difference
5=	When NDIS plans and funding are approved for health supports (e.g., helpful NDIS coordinators can improve access to services; reduces financial burden on families)	9%	9%	0%
5=	When health spaces are comfortable and sensory-friendly (e.g., calm waiting rooms; alternative meeting spaces; virtual reality; dim lights)	9%	6%	3%
9=	Health care providers having an awareness and knowledge of autism, the characteristics of autism (including sensory needs), and different presentations (including the presentation of autism in women or girls) (e.g., autism trained and experienced health care professionals; awareness of diversity in pain presentation)	6%	6%	0%
9=	When supports are provided that prepare Autistic individuals for accessing health care services or initiatives/ supports that help access to health services (e.g., preparation resources for Autistic individuals; access to support workers; educated carers/families; supports for families)	6%	8%	-2%

3.2.1.2 Autism Connect dataset: Contacts relating to physical health

A total of 21 contacts to Autism Connect referred to physical health-related issues, specifically in relation to Autistic LGBTIQ+ people. The most frequent physical health issues that the contact related to are reported within this section. Table 20 ranks the most frequent physical health-related issues that people contacted the Autism Connect helpline to discuss. The data are ranked from most frequently reported to least frequently reported issues. Where there was a difference of 5% or more between contacts related to Autistic LGBTIQ+ and all Autistic people, the percentage difference is highlighted with bold and underlined text in the tables.

Table 20: Most frequent physical health-related issues raised in contacts to Autism Connect by, or in relation to, Autistic LGBTIQ+ people

Topic (contacts)	Physical health issue raised	% contacts for physical health-related issues		
		For Autistic LGBTIQ+ people <i>n</i> = 21	All contacts <i>n</i> = 292	% difference between groups
Seeking therapist (<i>n</i> = 19)	Other physical health professionals	33.3%	21.2%	<u>12.1%</u>
	GP	23.8%	23.3%	0.5%
	Nutrition or dietetics	19.0%	19.2%	-0.2%
	Paediatrician	9.5%	14.7%	<u>-5.2%</u>
	Occupational therapist (physical health reasons)	4.8%	4.5%	0.3%
Advice (<i>n</i> = 2)	Physical health advice	9.5%	14.0%	-4.5%

3.2.1.3 “Barriers to care” questionnaire

Parents were not asked if their child identified as LGBTIQ+ in this questionnaire that asked them to rank predetermined statements relating to barriers to accessing acute physical health care. This highlights a clear need to work with this community to extend knowledge on this issue.

3.2.2 Mental health services

3.2.2.1 The “1,000 insights” community views survey mental health services

A total of 87 Autistic LGBTIQ+ people answered at least one of the four open-ended questions on mental health services. These four questions were:

- What are three problems that Autistic people experience when using, or trying to access, mental health services?
- What do you think is causing these problems?
- What do you think could prevent or reduce these problems?
- What is working well, or has worked well, for Autistic people when using or trying to access mental health services?

The most frequently reported responses to each of the questions are reported within this section. The tables include the proportion of Autistic LGBTIQ+ people who provided a response that was coded into this category (with examples of the responses coded into this category) alongside the proportion of all Autistic people who provided a response that was coded into this category. Where there was a difference of 5% or more between Autistic LGBTIQ+ people and all Autistic people, the percentage difference is highlighted with bold and underlined text in the tables.

3.2.2.1.1 Problems experienced by Autistic LGBTIQ+ people in relation to mental health services

A total of 85 Autistic LGBTIQ+ people opted to answer this open-ended question in relation to mental health services. Table 21 ranks the 10 problems that Autistic LGBTIQ+ people most frequently reported Autistic people experiencing in relation to the mental health service (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 21: Most frequently reported problems experienced by Autistic people in relation to mental health services, as reported by Autistic LGBTIQ+ people

Rank	Problems experienced by Autistic people in relation to mental health services	% who stated this answer		
		Autistic LGBTIQ+ people <i>n</i> = 85	Entire Autistic sample <i>n</i> = 250	% difference
1	Prohibitive cost (e.g., very expensive; services able to charge too much)	32%	28%	4%
2	Lack of knowledge or understanding of autism/neurodiversity, its presentation, and its impact across the lifespan (e.g., lack of knowledge about autism in females; lack of understanding of lived experience)	27%	28%	-1%
3	Insufficient availability/access of relevant, skilled mental health worker (e.g., lack of providers who can do assessments; challenges finding neurodivergent therapist)	21%	18%	3%
4	Long or closed waitlists (e.g. long waiting time to access diagnostic services, psychologists, and psychiatrists; waiting lists exacerbate issues)	19%	19%	0%
5=	Insufficient availability/access of appropriate services (e.g., lack of services specialising in autism; long distance to travel)	14%	17%	-3%
5=	Misdiagnosis of autism and/or co-occurring conditions (e.g., misdiagnosing autism as, for example, a personality disorder; diagnostic overshadowing)	14%	12%	2%
5=	Trivialising or not believing someone's autism diagnosis or their lived experience (e.g., not believing someone's experience)	14%	10%	4%

Rank	Problems experienced by Autistic people in relation to mental health services	% who stated this answer		
		Autistic LGBTIQA+ people <i>n</i> = 85	Entire Autistic sample <i>n</i> = 250	% difference
8=	Strategies not tailored for the individual client or neurodivergent people (e.g., not tailored for individual needs or preferred goals; neurotypical strategies do not always work for Autistic people)	12%	10%	2%
8=	Mental health services not providing autism diagnosis or recognising autism characteristics (e.g., challenges obtaining referral for diagnosis; lack of identification of autism characteristics)	12%	7%	<u>5%</u>
10	Concerns about professional's therapeutic skills (e.g., lack of genuine care; discriminatory towards Autistic people)	11%	10%	1%

3.2.2.1.2 Factors causing the problems experienced by Autistic people in relation to mental health services, as reported by Autistic LGBTIQ+ people

A total of 72 Autistic LGBTIQ+ people opted to answer this open-ended question on mental health services. Table 22 ranks the 10 most frequently reported factors that respondents felt were causing the problems that Autistic people experience in relation to mental health services reported above (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 22: Most frequently reported causes of the problems experienced by Autistic people in relation to mental health services, as reported by Autistic LGBTIQ+ people

Rank	Causes of the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic LGBTIQ+ people <i>n</i> = 72	Entire Autistic sample <i>n</i> = 213	% difference
1	Lack of, or poor quality of, training for mental health professionals (e.g., poor training; lack of training in diagnosing and treating autism appropriately)	32%	27%	5%
2	Lack of knowledge or understanding of autism and neurodivergent conditions, its presentation, and its impact (e.g., lack of understanding the heterogeneous presentation of autism; lack of understanding of stresses associated with autism)	24%	28%	-4%
3	Concern about therapeutic skills and/or attitude (e.g., lack of respect; ableism; not allowing time to develop relationship; ignorance)	18%	17%	1%
4	Insufficient funding (generally) (e.g., lack of funding; funding shortfall)	14%	15%	-1%
5=	Insufficient number of professionals with an interest/expertise in autism (e.g., lack of qualified people specialising in autism; lack of specialists in rural areas)	11%	12%	-1%
5=	Strategies and practices considered insufficient, inappropriate, or poor quality (e.g., lack of awareness of how to modify practices; neuronormative concepts of well-being applied to Autistic people)	11%	9%	2%

Rank	Causes of the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic LGBTIQA+ people <i>n</i> = 72	Entire Autistic sample <i>n</i> = 213	% difference
5=	Professionals may make assumptions or have preconceived ideas of autism (e.g., Autistic people are not competent; autism is a “male diagnosis”)	11%	8%	3%
5=	Lack of research and Autistic-informed care in mental health services (e.g., evidence base is needed for women and girls; lack of co-designing services with Autistic people)	11%	8%	3%
5=	Approaches currently focus on medical model rather than more inclusive approaches (e.g., medical model is a problem; interaction with society is the problem, not autism)	11%	6%	<u>5%</u>
10	Challenges around diagnosis (e.g., late diagnosis; lack of acceptance of self-diagnosis; misdiagnosis of autism)	10%	6%	4%

3.2.2.1.3 Factors that could prevent or reduce the problems experienced by Autistic people in relation to mental health services, as reported by Autistic LGBTIQ+ people

A total of 63 Autistic LGBTIQ+ people opted to answer this open-ended question on mental health services. Table 23 ranks the 10 most commonly reported factors that Autistic LGBTIQ+ people reported could prevent or reduce the problems that Autistic people experience in relation to accessing mental health services reported above (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 23: Most frequently reported factors that could prevent or reduce the problems experienced by Autistic people in relation to mental health services, as reported by Autistic LGBTIQ+ people

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic LGBTIQ+ people <i>n</i> = 63	Entire Autistic sample <i>n</i> = 199	% difference
1	Increase (access to) training for people working as mental health professionals to enhance their understanding of autism (and other neurodivergence), including training from Autistic people with lived experience (e.g., mandatory, regular training; Autistic informed/delivered training)	51%	46%	5%
2	Increase funding and/or affordability of mental health services across the lifespan (e.g., government funded functional capacity assessment; price caps and/or rebates)	19%	19%	0%
3	Facilitate changes to practice to focus on strengths, neurodiversity-affirming care, and skills relevant to supporting Autistic people (e.g., use social model rather than medical model; neurodiversity-affirming practice)	14%	10%	4%
4=	More mental health professionals, including those specialising in autism, and those who are Autistic/neurodivergent themselves (e.g., more doctors; more psychologists; create new roles and professions to support Autistic people; incentives for experts; alternative qualification pathways)	13%	19%	-6%
4=	Improve access to, and quality of, services (e.g., reduce the red tape; consideration of access for regional and rural areas; services for people with complex needs)	13%	9%	4%

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic LGBTIQA+ people <i>n</i> = 63	Entire Autistic sample <i>n</i> = 199	% difference
6	Make access and use of services easier and more autism-friendly (e.g., alternative methods to book appointments, increased flexibility of appointments; environment)	11%	10%	1%
7=	Enhance the quality of university education and number of places available (e.g., do not phase out psychology general registration pathway; provide education on neurodiversity-affirming practice; include information on co-occurring intellectual disability and other co-occurring conditions)	10%	9%	1%
7=	Education to support general public's understanding of autism (e.g., address stigma; publicity drives to debunk myths and attitudes)	10%	7%	3%
9=	More co-produced research that provides evidence-based practices for neurodivergent people (e.g., include Autistic and neurodivergent people in research design; research needed into neuro-affirmative practice)	8%	7%	1%
9=	Improved paths to diagnosis (e.g., quicker path to diagnosis; more psychologists able to diagnose)	8%	5%	3%

3.2.2.1.4 Factors that are working well, or have worked well, for Autistic people in relation to mental health services, as reported by Autistic LGBTIQ+ people

Overall, 45 Autistic LGBTIQ+ people replied to this open-ended question. Table 24 ranks the 10 most frequently reported factors that Autistic LGBTIQ+ people reported to be working well, or that have worked well, for Autistic people in relation to mental health (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 24: Most frequently reported factors that are working well, or have worked well, for Autistic people in relation to mental health services, as reported by Autistic LGBTIQ+ people

Rank	What is working well, or has worked well, in relation to Autistic people's experiences with mental health services	% who stated this answer		
		Autistic LGBTIQ+ people <i>n</i> = 45	Entire Autistic sample <i>n</i> = 155	% difference
1	When you find the right mental health professional for you, who is often knowledgeable/experienced about autism and its associated needs (e.g., understands autism and neurodiversity; experience working with Autistic people)	22%	18%	4%
2=	Nothing/not a lot	16%	25%	-9%
2=	When NDIS funding has been provided to support needs (e.g., NDIS can reduce mental health challenges when all needs are covered; supportive NDIS plan manager)	16%	13%	3%
4=	When alternative/flexible access are available (inc. making appointment and practice) (e.g., online chat services; alternative booking options such as leaving voice message or online portal)	13%	13%	0%
4=	When a professional has lived experience (e.g., are Autistic/neurodivergent, or have Autistic family members)	13%	10%	3%
4=	Understanding what is best for oneself and advocating for this (e.g., creating environments where you feel safe, finding a therapist who works for you, finding mental health services that give Autistic people agency, choice and empowerment as a mental health services user, self-advocacy)	13%	4%	9%

Rank	What is working well, or has worked well, in relation to Autistic people's experiences with mental health services	% who stated this answer		
		Autistic LGBTIQA+ people <i>n</i> = 45	Entire Autistic sample <i>n</i> = 155	% difference
7	The recent shift towards neurodiversity-affirming and strengths-based practice, rather than relying on medical model of disability (e.g., focus on the strengths of a person rather than the challenges)	11%	9%	2%
8=	Support from family, friends, and Autistic/neurodivergent community (e.g., parent advocacy; ability to bring trusted person to appointments; social groups to meet other Autistic people)	7%	8%	-1%
8=	A range of different approaches and modifications highlighting that no single approach is suitable for everyone (e.g., trauma-informed; assistance animals; art therapy; social skills sessions; psychotherapy; group sessions)	7%	6%	1%
8=	When you develop a safe, trusting, therapeutic relationship (e.g., feeling safe; building long-term relationship; continuity of care)	7%	5%	2%

3.2.2.2 Autism Connect dataset: Contacts relating to mental health

A total of 123 contacts to Autism Connect referred to mental health issues, specifically in relation to Autistic LGBTIQ+ people. The most frequent mental health issues that the contact related to are reported within this section. Table 25 ranks the most frequent mental health-related issues that people contacted the Autism Connect helpline to discuss. The data are ranked from most frequently reported to least frequently reported issues.

Table 25: Most frequent mental health-related issues raised in contacts to Autism Connect by, or related to, Autistic LGBTIQ+ people

Topic (contacts)	Mental health issue raised	% contacts for mental health-related issues		
		For Autistic LGBTIQ+ people <i>n</i> = 123	All contacts <i>n</i> = 1,514	% difference between groups
Seeking therapist (<i>n</i> = 98)	Psychologist	50.4%	55.2%	-4.8%
	Psychiatrist	10.6%	12.4%	-1.8%
	Counsellor	5.7%	3.1%	2.6%
	Other or unspecified mental health support	5.7%	5.6%	0.1%
	Seeking autism diagnosis prompted by mental health challenges	3.3%	1.9%	1.4%
	General therapists (mental health reasons)	1.6%	3.7%	-2.1%
	Unspecified therapist but specific goal or support relating to mental health	1.6%	0.8%	0.8%
	Occupational therapist (mental health reasons)	0.8%	1.2%	-0.4%
Funding information (<i>n</i> = 1)	Non-NDIS funding (mental health reasons)	0.8%	0.4%	0.4%

Topic (contacts)	Mental health issue raised	% contacts for mental health-related issues		
		For Autistic LGBTIQA+ people <i>n</i> = 123	All contacts <i>n</i> = 1,514	% difference between groups
Advice (<i>n</i> = 24)	Mental health advice	12.2%	10.3%	1.9%
	Work or employment impacting mental health	5.7%	2.0%	3.7%
	Education relating to mental health	1.6%	1.7%	-0.1%

3.2.2.3 “Making therapy better” questionnaire

A total of 10 respondents identified as Autistic LGBTIQ+ people in the questionnaire about ways of making mental health supports/therapy better for Autistic people. Here, Autistic people were asked how helpful specific activities, accommodations, or strategies would be if they were offered by a mental health practitioner or clinic. The five most helpful activities, accommodations, or strategies are listed in Table 26. Where there was a difference of 0.25 or more between Autistic LGBTIQ+ Autistic people and all Autistic people, the score difference is highlighted with bold and underlined text in the tables.

As this is the minimum sample size that is reported on in this report, significant caution should be applied to these findings.

Table 26: Five most helpful activities, accommodations, or strategies that could be offered by a mental health practitioner or clinic, as reported by Autistic LGBTIQ+ people

Activity, accommodation, or strategy	Mean (SD) Autistic LGBTIQ+ people <i>n</i> = 10	Mean (SD) entire Autistic sample <i>n</i> = 130	Score difference for Autistic LGBTIQ+ people
If the clinic provided the option to book online to make an appointment	5.00 (0.00)	4.78 (.64)	0.22
If the psychologist provided options to adjust the lighting in the therapy room and service to suit your sensory preferences (e.g., blinds)	5.00 (0.00)	4.22 (.98)	<u>0.78</u>
If the psychologist provided options to adjust the noise in the therapy room and service to suit your preferences (e.g., background music)	5.00 (0.00)	4.16 (1.05)	<u>0.84</u>
If the clinic provided information about the process of therapy and what to expect in a session before sessions	4.90 (0.32)	4.34 (.89)	<u>0.56</u>
If the clinic provided the option to text to make an appointment	4.80 (0.42)	4.50 (.99)	<u>0.30</u>

The five least helpful activities, accommodations, or strategies are listed in Table 27.

Table 27: Five least helpful activities, accommodations, or strategies that could be offered by a mental health practitioner or clinic, as reported by Autistic LGBTIQ+ people

Activity, accommodation, or strategy	Mean (SD) Autistic LGBTIQ+ people <i>n</i> = 10	Mean (SD) entire Autistic sample <i>n</i> = 130	Score difference for Autistic LGBTIQ+ people
If therapy is provided via telephone	2.30 (1.57)	2.14 (1.23)	0.16
If sessions were shorter (< 50 minutes)	2.40 (1.58)	2.10 (1.14)	<u>0.30</u>
If therapy is provided in groups with other Autistic people	2.60 (0.97)	2.32 (1.13)	<u>0.28</u>
If the psychologist involved a family member or partner in sessions	2.80 (0.92)	2.60 (1.30)	0.20
If therapy is provided online via video conferencing instead of in person (e.g., Zoom, Microsoft Teams)	2.90 (1.60)	3.19 (1.44)	<u>0.29</u>

3.2.3 Summary of existing data for Autistic LGBTIQ+ people

Prior to reading this section, it is important to note the small number of respondents who identified as LGBTIQ+ in the “Making therapy better” data. It is also important to note that information regarding whether or not somebody identified as LGBTIQ+ was not routinely reported for the Autism Connect helpline (it could only be inferred through the contact description), nor was it collected for the “Barriers to care” questionnaire. Further in-depth consultations are therefore needed to explore the health and mental health care service experiences of Autistic LGBTIQ+ people in Australia.

3.2.3.1 Summary of differences noted in the data for Autistic LGBTIQ+ people as compared to the data for the entire Autistic sample

The focus in this section is on any items that substantially differed between Autistic LGBTIQ+ people and the entire Autistic sample within each dataset. A general summary of the issues with health and mental health services raised by, or in relation to, Autistic LGBTIQ+ people is provided in Section 3.2.3.2.

Although there were some shared and similar responses to the questions relating to physical and mental health care service experiences of Autistic LGBTIQ+ people compared to the entire sample of Autistic people in the datasets, there were also **25 areas in which they differed substantially** (see Figure 2 and Figure 3). The process used and definitions of “substantial difference” are document in the method chapter.

A number of the areas where data provided by, or in relation to, Autistic LGBTIQ+ people indicated more challenges (as compared to the entire Autistic sample) focussed on adjustments and accommodations not being offered and on the fact that physical health care systems are based on neurotypical/majority needs and therefore do not take into account needs or preferences of Autistic people. More Autistic LGBTIQ+ people also indicated that accommodations to the physical environment would make psychological therapy better. More Autistic LGBTIQ+ people stated that health care works well for them when they understand what is best for oneself and advocate for this. They also highlighted the need for more training and information on autism.

Fewer Autistic LGBTIQ+ people identified funding of autism training and of resources as a problem than was reported in the entire Autistic sample.

Figure 2: Summary of substantial differences in existing datasets reporting on physical health service experiences for Autistic LGBTIQ+ people

In relation to physical health services, Autistic LGBTIQ+ people were more likely to...

- ▲ Make contact with Autism Connect, or have contact made about them, for assistance finding a health professional beyond a GP (+12.1%).
- ▲ Report that adjustments or accommodations not being offered, or systems not taking into account needs or preferences of Autistic people, is a problem (+7%; “1,000 insights” survey).
- ▲ Report increasing communication options to improve access to health care and access to information about health care could reduce problems (+7%; “1,000 insights” survey).
- ▲ Report that nothing/not a lot is working well or has worked well (+6%; “1,000 insights” survey).
- ▲ Report the prioritising of neurotypical/majority needs, ableism, and lack of neurodiversity-affirming practice is causing the problems (+5%; “1,000 insights” survey).
- ▲ Report the dismissing or excluding of an Autistic person or their family as causing the problems (+5%; “1,000 insights” survey).
- ▲ Report finding the right physical health provider for you, who was often described as knowledgeable about autism, understanding, caring, patient, and non-judgemental, as working/having worked well (+5%; “1,000 insights” survey).
- ▲ Report that increasing (access to) education, training, and upskilling programs for health care professionals and administrative staff about autism, characteristics, and health impacts could reduce the problems (+5%; “1,000 insights” survey).

In relation to physical health services, Autistic LGBTIQ+ people were less likely to...

- ▼ Report a lack of funding/resources and/or difficulty accessing these supports (including the high costs of health care) as causing the problems (-5%; “1,000 insights” survey).
 - ▼ Make contact with Autism Connect, or have contact made about them, for assistance finding a paediatrician (-5.2%).
 - ▼ Report that a lack of funding for autism education, training, and upskilling of physical health care professionals, is causing the problems (-6%; “1,000 insights” survey).
-

Figure 3: Summary of substantial differences in existing datasets reporting on mental health service experiences for Autistic LGBTIQ+ people

In relation to mental health services, Autistic LGBTIQ+ people were more likely to...

- ▲ Rate their psychologist providing options to adjust the noise in the therapy room and service to suit their preferences as a more helpful activity, accommodation or strategy (+0.84; “Making therapy better” questionnaire).
- ▲ Rate their psychologist providing options to adjust the lighting in the therapy room and service to suit their sensory preferences as a more helpful activity, accommodation or strategy (+0.78; “Making therapy better” questionnaire).
- ▲ View shorter sessions (<50 minutes) more favourably, even though it is still considered a less helpful activity, accommodation or strategy (+0.30; “Making therapy better” questionnaire).
- ▲ Rate their clinic providing information about the process of therapy and what to expect in a session before sessions as a more helpful activity, accommodation or strategy (+0.56; “Making therapy better” questionnaire).
- ▲ Rate therapy being provided in groups with other Autistic people more favourably, even though it is still one of the five less helpful activities, accommodations or strategies (+0.28; “Making therapy better” questionnaire).
- ▲ Report understanding what is best for oneself and advocating for this as working/having worked well (+9%; “1,000 insights” survey).
- ▲ Rate the clinic providing the option to text to make an appointment as a more helpful activity, accommodation or strategy (+0.3; “Making therapy better” questionnaire).
- ▲ Report mental health services not providing autism diagnosis or recognising autism characteristics as a problem (+5%; “1,000 insights” survey).
- ▲ Report lack of, or poor quality of, training for mental health professionals as a cause of the problems (+5%; “1,000 insights” survey).
- ▲ Report approaches currently focusing on the medical model, rather than more inclusive approaches, as a cause of the problems (+5%; “1,000 insights” survey).
- ▲ Report that increasing (access to) training for people working as mental health professionals to enhance their understanding of autism (and other neurodivergence), including training from Autistic people with lived experience, could reduce the problems (+5%; “1,000 insights” survey).

In relation to mental health services, Autistic LGBTIQ+ people were less likely to...

- ▼ Report that increasing mental health professionals, including those specialising in autism, and those who are Autistic/neurodivergent themselves, could reduce the problems (-6%; “1,000 insights” survey).
 - ▼ Report that nothing/not a lot is working well or has worked well (-9%; “1,000 insights” survey).
 - ▼ Rate therapy being provided online via video conferencing instead of in person as a helpful activity, accommodation or strategy (-0.29; “Making therapy better” questionnaire).
-

3.2.3.2 Summary of issues or experiences with physical and/or mental health services for Autistic people who identify as LGBTIQ+ as reported in the four datasets

The issues and experiences within physical health and mental health services have been described individually above. This section focuses on highlighting issues and/or experiences that were reported across both physical health and mental health services for Autistic people who identify as LGBTIQ+.

The data reflect information gathered in multiple ways: (a) open text answers to a survey, (b) rating level of agreement on a rating scale, and (c) contacting Autism Connect. Despite these differences in how the data were obtained, commonalities were identified across the physical and mental health service domains. These commonalities are discussed below. It is important, however, that responses unique to each individual domain or dataset are considered as these provide important insight in the challenges experienced within a specific service.

Factors common across both physical and mental health care services: Commonalities in the problems identified by Autistic LGBTIQ+ people across the physical and mental health service domains include:

- (a) professionals holding a **limited knowledge of autism**
- (b) the **reluctance of professionals to adapt practices/strategies** or accommodations to support Autistic people
- (c) Autistic people holding **concerns about the therapeutic skills** of professionals (e.g., exhibiting discriminatory behaviours or lack of empathy)
- (d) large or prohibitive **costs** associated with the service
- (e) professionals not believing or trivialising the experiences of Autistic people and
- (f) **long or closed waitlists** to access these services.

The first four themes (a to d) reported above also informed what Autistic LGBTIQ+ people perceive to be the causes of these problems, and strategies that could be used to reduce them. Specifically, **increasing funding** across the lifespan both through NDIS and other funding avenues was considered important. To support an **increase in the knowledge of professionals**, it was advocated that there be an **increase in the availability or quality of autism education and training** for professionals working in these domains. This increase in knowledge could, in turn, support professionals' confidence and capability to **tailor and select practice/strategies** (including **neurodiversity-affirming approaches**) and accommodations that are beneficial for Autistic LGBTIQ+ people, a factor that was highlighted as important in both the "1,000 insights" community views survey and the "Making therapy better" questionnaire. Increased quality and availability of training could also **enhance the therapeutic skills** of the professionals, creating a more trusting and beneficial therapeutic relationships.

3.2.4 Summary

There were a number of notable (substantial) differences between the experiences of the Autistic LGBTIQ+ community and the entire sample of Autistic people in this study within Australia. These differences need to be explored further in future community consultations to understand why these differences may be present in these datasets. Understanding the reasons for these differences may further illuminate the underlying factors influencing the physical and mental health care experiences of Autistic LGBTIQ+ people throughout Australia.

The commonalities across different domains and different data collection methods highlight the robust nature of these challenges experienced by Autistic LGBTIQ+ people. These commonalities provide ideal starting points for improvements to these service domains that could be beneficial for Autistic LGBTIQ+ people in Australia.

It is important to note that not all pre-existing datasets enquired as to the LGBTIQ+ status of the Autistic people who provided information (or for whom information was provided). Future work should ensure that these data are collected to help us better understand the experiences of this priority group.

3.3 Autistic people who live in rural, regional, and remote areas

3.3.1 Physical health services

3.3.1.1 The “1,000 insights” community views survey physical health services

A total of 49 Autistic people who live in rural, regional, or remote areas answered at least one of the four open-ended questions on physical health services. These questions were:

- What are three problems that Autistic people experience when accessing, or trying to access, physical health services?
- What do you think is causing these problems?
- What do you think could prevent or reduce these problems?
- What is working well, or has worked well, for Autistic people in relation to physical health care services?

The most frequently reported responses to each of the questions are reported within this section. The tables include the proportion of Autistic people who live in rural, regional, and remote areas who provided a response that was coded into this category (with examples of the responses coded into this category) alongside the proportion of all Autistic people who provided a response that was coded into this category. Where there was a difference of 5% or more between the Autistic people who live in rural, regional and remote areas and the data for all Autistic people, the percentage difference is highlighted with bold and underlined text in the tables.

3.3.1.1.1 Problems experienced by Autistic people who live in rural, regional, and remote areas in relation to physical health services

A total of 47 Autistic people who live in rural, regional, and remote areas opted to answer this open-ended question in relation to physical health services. Table 28 ranks the problems that Autistic people who live in rural, regional, and remote areas most frequently reported Autistic people experiencing in relation to physical health services (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 28: Most frequently reported problems experienced by Autistic people in relation to physical health services, as reported by Autistic people who live in rural, regional, and remote areas

Rank	Problems experienced by Autistic people in relation to physical health services	% who stated this answer		
		Autistic people who live in rural, regional and remote areas <i>n</i> = 47	Entire Autistic sample <i>n</i> = 253	% difference
1	Staff in health care settings (providers and administrative staff) have a poor understanding or knowledge of autism, how it presents in different people or contexts, and how it impacts the experience of health care settings (e.g., outdated knowledge of autism; lack of knowledge of how autism impacts the experience of health care settings)	34%	23%	<u>11%</u>
2	Physical health care providers dismissing or not believing the reports of Autistic people or their family members (including not believing a person is Autistic) (e.g., dismissing symptoms or requests)	30%	26%	4%
3	Long waiting lists to access physical health services (e.g., long waiting time to access diagnostic, generalised, and specialised services)	21%	13%	<u>8%</u>
4=	Services are too expensive to access (e.g., challenges accessing NDIS funding, insufficient Medicare rebates)	17%	13%	4%
4=	The sensory elements of physical health services or settings (including waiting rooms and emergency departments) are not supportive for Autistic people, sometimes leading to sensory overwhelm (e.g., crowded, bright and noisy waiting rooms)	17%	19%	-2%

Rank	Problems experienced by Autistic people in relation to physical health services	% who stated this answer		
		Autistic people who live in rural, regional and remote areas <i>n</i> = 47	Entire Autistic sample <i>n</i> = 253	% difference
6	Adjustments or accommodations not offered, or system not taking into account needs or preferences of Autistic people (e.g., appointments or therapies not autism-friendly; options for appointments [telehealth or in person]; and the process of arranging appointments or communicating with staff outside of appointments)	13%	15%	-2%
7=	Health professionals' reluctance to adapt practices or provide accommodations/supports for Autistic individuals (e.g., inflexibility, one-size-fits-all, lack of neurodiversity-affirming care)	11%	17%	-6%
7=	Challenges accessing sufficient funding to support physical health (e.g., Medicare support; bulk-billing services; NDIS funding)	11%	7%	4%
7=	Differences or difficulties with communication, including Autistic people experiencing challenges with describing their experiences, having to frequently repeat information to providers, and physical health providers not presenting information in a way that is accessible to Autistic people (e.g., difficulties or fears associated with articulating needs or feelings)	11%	17%	-6%

3.3.1.1.2 Factors causing the problems experienced by Autistic people who live in rural, regional, and remote areas in relation to physical health services

A total of 44 Autistic people who live in rural, regional, and remote areas opted to answer this open-ended question on physical health services. Table 29 ranks the eight most commonly reported factors that respondents felt were causing the problems that Autistic people experience in relation to physical health services reported above.

Table 29: Most frequently reported causes of the problems experienced by Autistic people in relation to physical health services, as reported by Autistic people who live in rural, regional, and remote areas

Rank	Causes of the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic people who live in rural, regional, and remote areas <i>n</i> = 44	Entire Autistic sample <i>n</i> = 226	% difference
1	Staff in health care settings (including administrative settings) have a lack of knowledge or understanding of autism/neurodiversity, diversity of presentations, and how autism/neurodivergence may impact physical health needs or symptoms, such as pain (e.g., lack of understanding individual needs; lack of understanding of autism; outdated knowledge)	34%	32%	2%
2	Lack of funding for autism education, training, and upskilling of physical health care professionals (e.g., lack of training within undergraduate and postgraduate level; insufficient ongoing professional development and Autistic-led training)	27%	26%	1%
3	Lack of funding/resources and/or difficulty accessing these supports (including the high costs of health care) (e.g., very expensive; funding shortfall; limited bulk-billing services)	18%	18%	0%
4	Insufficient number of available health care professionals (e.g., lack of professionals entering the field; lack of staff retention and incentives; a lack of university placements to train new professionals)	16%	10%	6%

Rank	Causes of the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic people who live in rural, regional, and remote areas <i>n</i> = 44	Entire Autistic sample <i>n</i> = 226	% difference
5	Neurotypical/majority needs prioritised, ableism, and lack of neurodiversity-affirming practice (e.g., services are not designed to be inclusive of Autistic people; there is an emphasis on the needs of the practitioner and non-Autistic clients)	11%	13%	-2%
6=	A system with overwhelmed and overworked staff, time pressures, and insufficient resources (e.g., being rushed; no time for extra accommodations)	9%	7%	2%
6=	Lack of government support and guidance (e.g., a lack of autism-specific research; lack of guidelines/policy; increased red tape and bureaucracy)	9%	10%	-1%
6=	Insufficient number of professionals or services with an interest/expertise in autism (e.g., a lack of Autistic professionals or those with lived experience; a lack of specialists in rural areas)	7%	6%	1%

3.3.1.1.3 Factors that could prevent or reduce the problems experienced by Autistic people who live in rural, regional, and remote areas in relation to physical health services

A total of 44 Autistic people who live in rural, regional, and remote areas opted to answer this open-ended question on physical health services. Table 30 ranks the 10 most commonly reported factors that Autistic people who live in rural, regional, and remote areas reported could prevent or reduce the problems that Autistic people experience in relation to accessing physical health services reported above.

Table 30: Most frequently reported factors that could prevent or reduce the problems experienced by Autistic people in relation to physical health services, as reported by Autistic people who live in rural, regional, and remote areas

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic people who live in rural, regional, and remote areas <i>n</i> = 44	Entire Autistic sample <i>n</i> = 210	% difference
1	Increase (access to) education, training, and upskilling programs for health care professionals and administrative staff about autism, characteristics, and health impacts (e.g., mandatory onboarding; Autistic informed/delivered training; and university level training)	50%	51%	-1%
2	Increase the number of health care professionals and health services available (e.g., incentives to increase rural/regional service; broadening scope of practice for health professionals)	20%	13%	<u>7%</u>
3	Increase access and use of physical health care services for Autistic people and their families through the provision of accommodations, flexible access options, and supports (e.g., increased flexibility; and increased access to supports)	14%	14%	0%
4=	Increase funding/resources and/or affordability of health services across the lifespan (e.g., increasing access to funding; increasing bulk-billing services; reviewing funding systems such as NDIS)	14%	17%	-3%
4=	Increase communication options to improve access to health care and access to information about health care (e.g., web-based booking systems; text-based communication; opting in or out of telehealth [i.e., not assuming it is preferred or unpreferred])	14%	17%	-3%

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic people who live in rural, regional, and remote areas <i>n</i> = 44	Entire Autistic sample <i>n</i> = 210	% difference
6=	Listen, validate and take concerns of Autistic individuals and their families/carers seriously (e.g., asking questions, working in partnership with clients)	11%	9%	2%
6=	Government reform, support, and guidance (e.g., investment in research and services; guidelines, policy and regulations)	11%	14%	-3%
6=	Reducing the cost of health care services (including medications, diagnosis, and health care programs) (e.g., Medicare rebates for autism assessments; access to free programs and services)	11%	6%	<u>5%</u>
9=	Actively employ, consult, and collaborate with neurodivergent practitioners, support workers, advocates, and those in leadership/decision-making roles (e.g., consult with Autistic people when designing or developing services; services actively employing neurodivergent practitioners, support workers, advocates)	9%	10%	-1%
9=	Increase community awareness about autism (e.g., public education programs, media campaigns, wider dissemination of knowledge, reducing stigma/stereotypes)	9%	5%	4%

3.3.1.1.4 Factors that are working well, or have worked well, for Autistic people who live in rural, regional, and remote areas in relation to physical health services

Overall, 34 Autistic people who live in rural, regional, and remote areas replied to this open-ended question. Table 31 ranks the eight most commonly reported factors that Autistic people who live in rural, regional, and remote areas reported to be working well, or that have worked well, for Autistic people in relation to physical health services.

Table 31: Most frequently reported factors that are working well, or have worked well, in relation to Autistic people accessing physical health services, as reported by Autistic people who live in rural, regional, and remote areas

Rank	What is working well, or has worked well, in relation to Autistic people’s experiences with physical health services	% who stated this answer		
		Autistic people who live in rural, regional, and remote areas <i>n</i> = 34	Entire Autistic sample <i>n</i> = 161	% difference
1	Nothing/not a lot	26%	28%	-2%
2	When you find the right physical health provider for you, who was often described as knowledgeable about autism, understanding, caring, patient, and non- judgemental (e.g., compassionate; gentle; empathetic)	24%	21%	3%
3	When NDIS plans and funding are approved for health supports (e.g., helpful NDIS coordinators can improve access to services; reduces financial burden on families)	18%	9%	9%
4=	When health care providers proactively ask about and provide alternative/flexible access, accommodations, and/or support for Autistic individuals (e.g., longer appointments; more flexibility with appointments; support people attending; home visits)	12%	9%	3%
4=	When providers ask questions and listen to Autistic people and/or their family members, and include Autistic individuals and their families in health care decisions (e.g., open communication; respectful practice; seeking consent, preferences and opinions)	12%	8%	4%

Rank	What is working well, or has worked well, in relation to Autistic people's experiences with physical health services	% who stated this answer		
		Autistic people who live in rural, regional, and remote areas <i>n</i> = 34	Entire Autistic sample <i>n</i> = 161	% difference
4=	When health care services are affordable and there is access to funding (beyond NDIS) (e.g., Medicare rebates; bulkbilling; and Health Care cards)	12%	6%	6%
4=	When there are increased communication options to improve access to, and information about, health care (e.g., web-based booking systems; option of telehealth; non-verbal communication options)	12%	12%	0%
9	When supports are provided that prepare Autistic individuals for accessing health care services or initiatives/ supports that help access to health services (e.g., preparation resources for Autistic individuals; access to support workers; educated carers/families; supports for families)	9%	8%	1%

3.3.1.2 Autism Connect dataset: Contacts relating to physical health

A total of six contacts to Autism Connect referred to physical health-related issues, specifically by, or related to, Autistic people who live in rural, regional and remote areas. This is not a sufficient number of people from which to draw conclusions, and highlights a clear need to work with this community to extend knowledge on this issue.

3.3.1.3 “Barriers to care” questionnaire

Geographical position was not collected as part of this questionnaire that asked respondents to rank predetermined statements relating to barriers to accessing acute physical health care. Hence data cannot be extracted for this priority group. This highlights a clear need to work with this community to extend knowledge on this issue.

3.3.2 Mental health services

3.3.2.1 The “1,000 insights” community views survey mental health services

A total of 55 Autistic people who live in regional, and remote areas answered at least one of the four open-ended questions on mental health services. These four questions were:

- What are three problems that Autistic people experience when using, or trying to access, mental health services?
- What do you think is causing these problems?
- What do you think could prevent or reduce these problems?
- What is working well, or has worked well, for Autistic people when using or trying to access mental health services?

The most frequently reported responses to each of the questions are reported within this section. The tables include the proportion of Autistic people who live in regional, rural, and remote areas who provided a response that was coded into this category (with examples of the responses coded into this category) alongside the proportion of all Autistic people who provided a response that was coded into this category. Where there was a difference of 5% or more between the Autistic people who live in regional, rural, and remote areas and all Autistic people, the percentage difference is highlighted with bold and underlined text in the tables.

3.3.2.1.1 Problems experienced by Autistic people who live in rural, regional, and remote areas in relation to mental health services

A total of 53 Autistic people who live in rural, regional, and remote areas opted to answer this open-ended question in relation to mental health services. Table 32 ranks the problems that Autistic people who live in rural, regional, and remote areas most frequently reported Autistic people experiencing in relation to mental health services (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 32: Most frequently reported problems experienced by Autistic people in relation to mental health services, as reported by Autistic people who live in rural, regional, and remote areas

Rank	Problems experienced by Autistic people in relation to physical health services	% who stated this answer		
		Autistic people who live in regional, rural and remote areas <i>n</i> = 53	Entire Autistic sample <i>n</i> = 250	% difference
1	Lack of knowledge or understanding of autism/neurodiversity, its presentation, and its impact across the lifespan (e.g., lack of knowledge about autism in females; lack of understanding of lived experience)	32%	28%	4%
2	Prohibitive cost (e.g., very expensive; services able to charge too much)	26%	28%	-2%
3	Long or closed waitlists (e.g. long waiting time to access diagnostic services, psychologists, and psychiatrists; waiting lists exacerbate issues)	23%	19%	4%
4	Insufficient availability/access of appropriate services (e.g., lack of services specialising in autism; long distance to travel)	21%	17%	4%
5	Insufficient availability/access of relevant, skilled mental health worker (e.g., lack of providers who can do assessments; challenges finding neurodivergent therapist)	17%	18%	-1%

Rank	Problems experienced by Autistic people in relation to physical health services	% who stated this answer		
		Autistic people who live in regional, rural and remote areas <i>n</i> = 53	Entire Autistic sample <i>n</i> = 250	% difference
6	Strategies not tailored for the individual client or neurodivergent people (e.g., not tailored for individual needs or preferred goals; neurotypical strategies do not always work for Autistic people)	13%	10%	3%
7	Misdiagnosis of autism and/or co-occurring conditions (e.g., misdiagnosing autism as, for example, a personality disorder; diagnostic overshadowing)	11%	12%	-1%
8=	Concerns about a professional's therapeutic skills (e.g., lack of genuine care; discriminatory towards Autistic people)	9%	10%	-1%
8=	Difficulty communicating about mental health conditions and related experiences (e.g., difficulty identifying emotions in order to talk about them; being non-speaking; challenges identifying internal experiences)	9%	6%	3%
10=	Trivialising or not believing someone's autism diagnosis or their lived experience (e.g., not believing someone's experience)	8%	10%	-2%
10=	Professionals may make assumptions or have pre-conceived ideas of autism, holding a deficit-based view (e.g., stereotyping; behaviours viewed as attention seeking)	8%	10%	-2%
10=	Challenges in forming therapeutic relationship (e.g., high turnover of staff impacting relationship building; limited time with therapist; practitioner poorly matched with client; not making client feel safe)	8%	4%	4%

3.3.2.1.2 Factors causing the problems experienced by Autistic people in relation to mental health

A total of 46 Autistic people who live in rural, regional, and remote areas opted to answer this open-ended question on mental health services. Table 33 ranks the 12 most commonly reported factors that respondents felt were causing the problems that Autistic people experience in relation to mental health services reported services above (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 33: Most frequently reported causes of the problems experienced by Autistic people in relation to mental health services, as reported by Autistic people who live in rural, regional, and remote areas

Rank	Causes of the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic people who live in rural and remote areas <i>n</i> = 46	Entire Autistic sample <i>n</i> = 213	% difference
1	Lack of knowledge or understanding of autism and neurodivergent conditions, its presentation, and its impact (e.g., lack of understanding the heterogeneous presentation of autism; lack of understanding of stresses associated with autism)	32%	28%	4%
2	Lack of, or poor quality of, training for mental health professionals (e.g., poor training; lack of training in diagnosing and treating autism appropriately)	24%	27%	-3%
3=	Insufficient funding (generally) (e.g., lack of funding; funding shortfall)	17%	15%	2%
3=	Insufficient number of professionals with an interest/expertise in autism (e.g., lack of qualified people specialising in autism; lack of specialists in rural areas)	17%	12%	<u>5%</u>
5	Professionals may make assumptions or have preconceived ideas of autism (e.g., assumption that Autistic people are not competent; stigma around autism; misconception that autism is a “male diagnosis”)	15%	8%	<u>7%</u>

Rank	Causes of the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic people who live in rural and remote areas <i>n</i> = 46	Entire Autistic sample <i>n</i> = 213	% difference
6=	Concern about therapeutic skills and/or attitude (e.g., lack of respect; ableism; not allowing time to develop relationship; ignorance)	13%	17%	-4%
6=	Impact of decisions made by the government (e.g., government policies; government cuts; poor management of mental health services)	13%	10%	3%
8	Strategies and practices considered insufficient, inappropriate, or poor quality (e.g., lack of awareness of how to modify practices; neuronormative concepts of well-being applied to Autistic people)	11%	9%	2%
9=	Challenges with Medicare support (e.g., no funding for autism assessment/therapy for people older than 15 years; out of pocket costs too high)	7%	8%	-1%
9=	Lack of research and Autistic-informed care in mental health services (e.g., evidence base is needed for women and girls; lack of co-designing services with Autistic people)	7%	8%	1%
9=	Overwhelmed system/professionals with insufficient resources (e.g., lack of resources; overwhelmed staff; time pressure)	7%	7%	0%
9=	Increase quality in training, and number of students, focussing on mental health at university and/or further education (e.g., more clinical psychology places needed; more effective training for mental health professionals)	7%	6%	1%

3.3.2.1.3 Factors that could prevent or reduce the problems experienced by Autistic people who live in rural, regional, and remote areas in relation to mental health services

A total of 46 Autistic people who live in rural, regional, and remote areas opted to answer this open-ended question on mental health services. Table 34 ranks the 11 most commonly reported factors that Autistic people who live in regional, rural, and remote areas reported could prevent or reduce the problems that Autistic people experience in relation to accessing mental health services reported above (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 34: Most frequently reported factors that could prevent or reduce the problems experienced by Autistic people in relation to accessing mental health services, as reported by Autistic people who live in rural, regional, and remote areas

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic people who live in rural and remote areas <i>n</i> = 46	Entire Autistic sample <i>n</i> = 199	% difference
1	Increase (access to) training for people working as mental health professionals to enhance their understanding of autism (and other neurodivergence), including training from Autistic people with lived experience (e.g., mandatory, regular training; Autistic informed/delivered training)	50%	46%	4%
2	Increase funding and/or affordability of mental health services across the lifespan (e.g., government funded functional capacity assessment; price caps and/or rebates)	24%	19%	5%
3	More mental health professionals, including those specialising in autism, and those who are Autistic/neurodivergent themselves (e.g., more doctors; more psychologists; create new roles and professions to support Autistic people; incentives for experts; alternative qualification pathways)	22%	19%	3%
4	Enhance the quality of university education and number of places available (e.g., do not phase out psychology general registration pathway; provide education on neurodiversity-affirming practice; include information on co-occurring intellectual disability and other co-occurring conditions)	15%	9%	6%

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic people who live in rural and remote areas <i>n</i> = 46	Entire Autistic sample <i>n</i> = 199	% difference
5	Improved paths to diagnosis (e.g., quicker path to diagnosis; more psychologists able to diagnose)	13%	5%	8%
6	Implement Medicare-specific improvements for increasing affordability of mental health care (e.g., allow provisional psychologists to work under Medicare; Medicare funding for mental health)	11%	9%	2%
7	Make access and use of services easier and more autism-friendly (e.g., alternative methods to book appointments, increased flexibility of appointments; environment)	9%	10%	-1%
8=	Enhance the therapeutic skills and awareness of mental health professionals to support their work with Autistic clients (e.g., listen to [and believe] the client to identify challenges; account for possible challenges in identifying emotions or forming trust)	7%	11%	-4%
8=	Improve access to, and quality of, services (e.g., reduce the red tape; consideration of access for regional and rural areas; services for people with complex needs)	7%	9%	-2%
8=	Implement NDIS specific improvements for funding access (e.g., more inclusive funding; automatic access to NDIS for Autistic people)	7%	7%	0%
8=	Government reform and support of mental health sector (e.g., legislation around language use; better legislation for protecting clients against poor treatment)	7%	7%	0%

3.3.2.1.4 Factors that are working well, or have worked well, for Autistic people who live in rural, regional, and remote areas in relation to mental health services

Overall, 39 Autistic people who live in rural, regional, and remote areas replied to this open-ended question. Table 35 ranks the most commonly reported factors that Autistic people who live in rural, regional, and remote areas reported to be working well, or that have worked well, for Autistic people in relation to mental health.

Table 35: Most frequently reported factors that are working well, or have worked well, in relation to Autistic people accessing mental health services, as reported by Autistic people who live in regional, rural, and remote areas

Rank	What is working well, or has worked well, in relation to Autistic people’s experiences with mental health services	% who stated this answer		
		Autistic people who live in regional, rural, and remote areas <i>n</i> = 39	Entire Autistic sample <i>n</i> = 155	% difference
1	Nothing/not a lot	26%	25%	1%
2	When NDIS funding has been provided to support needs (e.g., NDIS can reduce mental health challenges when all needs are covered; supportive NDIS plan manager)	18%	13%	<u>5%</u>
3	When you find the right mental health professional for you, who is often knowledgeable/experienced about autism and its associated needs (e.g., understands autism and neurodiversity; experience working with Autistic people)	15%	18%	-3%
4=	When alternative/flexible access are available (inc. making appointment and practice) (e.g., online chat services; alternative booking options such as leaving voice message or online portal)	13%	13%	0%
4=	Accommodations to support Autistic people (e.g., informing clients of the steps; providing processing time; writing summaries of key ideas; more frequent shorter sessions; autism friendly sensory environments)	13%	7%	<u>6%</u>

Rank	What is working well, or has worked well, in relation to Autistic people's experiences with mental health services	% who stated this answer		
		Autistic people who live in regional, rural, and remote areas <i>n</i> = 39	Entire Autistic sample <i>n</i> = 155	% difference
6	The recent shift towards neurodiversity-affirming and strengths-based practice, rather than relying on medical model (e.g., focus on the strengths of a person rather than the challenges)	10%	9%	1%
7=	When a professional has lived experience (e.g., are Autistic/neurodivergent, or have Autistic family members)	8%	10%	-2%
7=	Affordable health care when it is accessible (e.g., cheap or bulk billed services with health care card; professions registered within "better access to mental health"; twenty extra sessions during COVID)	8%	7%	1%
7=	When a professional has good therapeutic skills (e.g., compassionate, flexible, listens, patient, speaking calmly)	8%	6%	2%
10=	Support from family, friends, and Autistic/neurodivergent community (e.g., parent advocacy; ability to bring trusted person to appointments; social groups to meet other Autistic people)	5%	8%	-3%
10=	A range of different approaches and modifications highlighting that no single approach is suitable for everyone (e.g., trauma-informed; assistance animals; art therapy; social skills sessions; psychotherapy; group sessions)	5%	6%	1%
10=	Understanding what is best for oneself and advocating for this (e.g., creating environments where Autistic people feel safe; finding a therapist who works for the individual; mental health services that give Autistic people agency, choice and empowerment; self-advocacy)	5%	4%	1%
10=	Co-designed training to help enhance understanding of autism and neurodiversity (e.g., therapists voluntarily doing training; therapists who have listened to, and learned from, Autistic adults; free training programs at university clinics and public hospitals)	5%	1%	4%

3.3.2.2 Autism Connect dataset: Contacts relating to mental health

A total of 17 contacts to Autism Connect referred to mental health issues, specifically in relation to Autistic people who live in regional, rural and remote areas. The most frequent mental health issues that the contact related to are reported within this section. Table 36 ranks the most frequent mental health-related issues that people contacted Autism Connect to discuss. The data are ranked from most frequently reported to least frequently reported issues. Where there was a difference of 5% or more between the contacts related to Autistic people who live in regional, rural and remote areas and all Autistic people, the percentage difference is highlighted with bold and underlined text in the tables.

It is important to consider the small sample size ($n < 20$) for this priority group when interpreting the results.

Table 36: Most frequent mental health-related issues raised in contacts to Autism Connect by, or related to, Autistic people who live in regional, rural and remote areas

Topic (contacts)	Mental health issue raised	% contacts for mental health-related issues		
		For Autistic women and girls <i>n</i> = 17	All contacts <i>n</i> = 1,514	% difference between groups
Seeking therapist (<i>n</i> = 17)	Psychologist	64.7%	55.2%	<u>9.5%</u>
	Other or unspecified mental health support	17.6%	5.6%	<u>12%</u>
	General therapists (mental health reasons)	5.9%	3.7%	2.2%
	Specific mental health goal or support	5.9%	0.8%	<u>5.1%</u>
	Psychiatrist	5.9%	12.4%	<u>-6.5%</u>

3.3.2.3 “Making therapy better” questionnaire

Geographical position was not collected as part of this dataset so data cannot be extracted for this priority group. This highlights a clear need to work with this community to extend knowledge on this issue.

3.3.3 Summary of existing data for Autistic people who live in regional, rural, and remote areas

3.3.3.1 Summary of differences noted in the data for Autistic people who live in regional, rural, or remote areas as compared to the data for the entire Autistic sample

The focus here is on any items that differed within datasets provided by, or in relation to, Autistic people living in rural, regional, or remote areas, and the data for the entire Autistic sample. A general summary of the issues with health and mental health services raised by, or in relation to, Autistic people living in rural, regional, or remote areas is provided in Section 3.3.3.2.

Although there are similarities in the physical and mental health care service experiences of Autistic people who live in rural, regional, and remote areas compared to the entire sample of Autistic people in this study, there were also 20 areas in which they differed substantially (see Figure 4 and Figure 5).

When the items in Figures 4 and 5 are considered together, it can be seen that Autistic people living in regional, rural, or remote areas are more likely to identify challenges in finding physical health or mental health practitioners. This is clearly reflected through the Autism Connect dataset, where 9-11% more people made contact in relation to someone from regional, rural or remote settings to find mental health practitioners. Autistic people from rural, regional or remote areas are also more likely to report long waiting lists as a problem, and report staff in health care settings (providers and administrative staff) having poor understanding or knowledge of autism. They also were more likely to highlight that health care works well when funding (e.g., NDIS) is approved or in place for health supports and/or when health care is affordable.

Understandably, if Autistic people living in regional, rural, or remote areas find it more challenging to find a practitioner with knowledge of autism who has availability, then they are less likely to highlight challenges with specifics within the appointments (e.g., accommodations, communication methods used) within their top three issues or problems.

Figure 4: Summary of substantial differences in existing datasets reporting on physical health service experiences for Autistic people living in rural, regional, or remote areas

In relation to physical health services, Autistic people from rural, regional and remote areas were more likely to...

- ▲ Report staff in health care settings (providers and administrative staff) having poor understanding or knowledge of autism, how it presents in different people or contexts, and how it impacts the experience of health care settings, as a problem (+11%; “1,000 insights” survey).
- ▲ Report when NDIS plans and funding are approved for health supports as working/having worked well (+9%; “1,000 insights” survey).
- ▲ Report long waiting lists as a problem (+8%; “1,000 insights” survey).
- ▲ Report increasing the number of health care professionals and health services available could reduce the problems (+7%; “1,000 insights” survey).
- ▲ Report there is an insufficient number of available health care professionals (+6%; “1,000 insights” survey).
- ▲ Report that affordable services, and access to funding (beyond NDIS) is working/has worked well (+6%; “1,000 insights” survey).
- ▲ Report that reducing the cost of health care services (including medications, diagnosis and health care programs) could reduce the problems (+5%; “1,000 insights” survey).

In relation to physical health care services, Autistic people from rural, regional and remote areas were less likely to...

- ▼ Report health professionals’ reluctance to adapt practices or provide accommodations/ supports for Autistic individuals as a problem (-6%; “1,000 insights” survey).
 - ▼ Report differences or difficulties with communication, including Autistic people experiencing challenges with describing their experiences, having to frequently repeat information to providers, and physical health providers not presenting information in a way that is accessible to Autistic people, as a problem (-6%; “1,000 insights” survey).
-

Figure 5: Summary of substantial differences in existing datasets reporting on mental health service experiences for Autistic people living in rural, regional, and remote areas

In relation to mental health services, Autistic people from rural, regional and remote backgrounds were more likely to...

- ▲ Make contact with Autism Connect, or have contact made about them, for other or unspecified mental health support (+12%).
- ▲ Make contact with Autism Connect, or have contact made about them, for assistance finding a psychologist (+9.5%).
- ▲ Report that improved paths to diagnosis could reduce problems (+8%; “1,000 insights” survey).
- ▲ Report professionals making assumptions or having preconceived ideas of autism as a cause of the problems (+7%; “1,000 insights” survey).
- ▲ Report enhancing the quality of university education and number of places availability could reduce the problems (+6%; “1,000 insights” survey).
- ▲ Report when accommodations are made to support Autistic people as working/having worked well (+6%; “1,000 insights” survey).
- ▲ Make contact with Autism Connect, or have contact made about them, for a specific goal or support (+5.1%).
- ▲ Report an insufficient number of professionals with an interest/expertise in autism as a cause of the problems (+5%; “1,000 insights” survey).
- ▲ Report increasing funding and/or affordability of mental health services across the lifespan could reduce the problems (+5; “1,000 insights” survey).
- ▲ Report when NDIS funding has been provided to support needs as working/having worked well (+5%; “1,000 insights” survey).

In relation to mental health services, Autistic people from rural, regional and remote backgrounds were less likely to...

- ▼ Make contact with Autism Connect, or have contact made about them, for assistance finding a psychiatrist (-6.5%).
-

3.3.3.2 Summary of issues or experiences with physical and/or mental health services for Autistic people living in regional, rural, or remote areas, as reported in the existing datasets

The issues and experiences within physical health and mental health services have been described individually above. This section focuses on the areas highlighted across both physical health and mental health services for Autistic people living in regional, rural, or remote locations.

The data reflect information gathered in multiple ways: (a) open text answers to a survey, and (b) contacting the Autism Connect helpline. The datasets that used level of agreement (i.e., “Barriers to care” questionnaire and “Making therapy better” questionnaire) did not gain information pertaining to the location of those who completed the questionnaires. Despite these differences in how the data were obtained, commonalities were identified across the responses provided in the physical and mental health service domains.

Factors common across physical and mental health services: Commonalities in the problems identified by Autistic people living in regional, rural, and remote areas across the physical and mental health service domains include: (a) professionals holding a **limited knowledge about autism**, (b) professionals **dismissing or not believing the experiences** of Autistic people, (c) large or prohibitive **costs** associated with the service, (d) the **lack of provision of adapted practices/strategies** or accommodations to support Autistic people, (e) **communication difficulties and/or differences**, including in accessing services (e.g., preferences for online booking systems), and (f) **long or closed waitlists** to access these services.

The first five themes (a to e) reported above were further reflected in what Autistic people living in regional, rural, and remote areas perceive to be the causes of these problems, and strategies that could be used to reduce them. Specifically, **lack of autism knowledge held by professionals** was considered a cause of the challenges Autistic people experience in physical and mental health services. To support an increase in the knowledge of professionals, it was suggested that there should be an **increase in the quality of, and access to, training** and university education related to autism. This increase in knowledge may lead to **more professionals listening to Autistic people** and their families, rather than dismissing their lived experiences. It could also support professionals to make **informed decisions regarding accommodations, strategies, and practices** (including neurodiversity-affirming approaches) to support Autistic people within these service areas. Such accommodations included considering ways to **support the communication differences** and preferences of the Autistic community, such as supporting access to, and use of, services via **increasing communication options** (e.g., telehealth, use of augmented and alternative communication, online booking options). Finally, increasing the affordability of these services by considering price structures and **increasing funding** across the lifespan was considered important.

Challenges in accessing services waitlists could be reflected in the substantially greater number of contacts to Autism Connect made by or in relation to regional, rural, and remote people asking for mental health professionals. This included psychologists and non-psychology mental health professional. Insufficient data was available to draw conclusions regarding the number of contacts placed to Autism Connect in search of physical health professionals.

3.3.4 Summary

There were a number of notable (substantial) differences between the experiences of the Autistic community who live in regional, rural, and remote areas and the entire sample of Autistic people in this study within Australia. These differences need to be explored further in future community consultations to understand the impact of these differences on physical and mental health outcomes.

It is worth noting that only a small number of Autistic people identified as living in regional, rural, or remote areas and that living in a rural or remote area may result in different physical or mental health outcomes from those living in regional areas. Some tentative conclusions can be reached based on the small number of respondent responses summarised in this report; however, we must be cautious in overinterpreting or over relying on these findings. This highlights that much more research and consultation is needed to better understand the experiences of Autistic people living in rural or remote areas specifically.

3.4 Autistic people from low socio-economic backgrounds

3.4.1 Physical health services

3.4.1.1 The “1,000 insights” community views survey physical health services

A total of 32 Autistic people who are from low socio-economic backgrounds (i.e., those who described themselves as “Poor” $n = 19$ or “Very Poor” $n = 13$) answered at least one of the four open-ended questions on physical health services. These questions were:

- What are three problems that Autistic people experience when accessing, or trying to access, physical health services?
- What do you think is causing these problems?
- What do you think could prevent or reduce these problems?
- What is working well, or has worked well, for Autistic people in relation to physical health care services?

The most frequently reported responses to each of the questions are reported within this section. The tables include the proportion of Autistic people who are from low socio-economic backgrounds who provided a response that was coded into this category (with examples of the responses coded into this category) alongside the proportion of all Autistic people who provided a response that was coded into this category. Where there was a difference of 5% or more between Autistic people who are from low socio-economic backgrounds and all Autistic people, the percentage difference is highlighted with bold and underlined text in the tables.

3.4.1.1.1 Problems experienced by Autistic people who are from low socio-economic backgrounds in relation to physical health service

A total of 32 Autistic people who are from low socio-economic backgrounds opted to answer this open-ended question in relation to physical health services. Table 37 ranks the problems that Autistic people who are from low socio-economic backgrounds most frequently report Autistic people experiencing in relation to physical health services (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 37: Most frequently reported problems experienced by Autistic people in relation to physical health services, as reported by Autistic people from low socio-economic backgrounds

Rank	Problems experienced by Autistic people in relation to physical health services.	% who stated this answer		
		Autistic people who are from low socio-economic backgrounds <i>n</i> = 32	Entire Autistic sample <i>n</i> = 253	% difference
1	Health professionals' reluctance to adapt practices or provide accommodations/supports for Autistic individuals (e.g., inflexibility, one-size-fits-all, lack of neurodiversity-affirming care)	34%	17%	<u>17%</u>
2	Physical health care providers dismissing or not believing the reports of Autistic people or their family members (including not believing a person is Autistic) (e.g., dismissing symptoms or requests)	31%	26%	<u>5%</u>
3=	Staff in health care settings (providers and administrative staff) have a poor understanding or knowledge of autism, how it presents in different people or contexts, and how it impacts the experience of health care settings (e.g., outdated knowledge of autism; lack of knowledge of how autism impacts the experience of health care settings)	25%	23%	2%
3=	Concerns about professional's therapeutic skills (e.g., lack of patience, empathy, care or understanding; mistreatment)	25%	16%	<u>9%</u>

Rank	Problems experienced by Autistic people in relation to physical health services.	% who stated this answer		
		Autistic people who are from low socio-economic backgrounds <i>n</i> = 32	Entire Autistic sample <i>n</i> = 253	% difference
5	The sensory elements of physical health services or settings (including waiting rooms and emergency departments) are not supportive for Autistic people, sometimes leading to sensory overwhelm (e.g., crowded, bright and noisy waiting rooms)	22%	19%	3%
6=	Difficulties with the process to access and physically attend health services (e.g., organising and understanding forms, service availability/options, paperwork and appointments; transport)	19%	12%	<u>7%</u>
7=	Poor clinical decisions (e.g., misdiagnosing, reactive not preventative focus)	13%	9%	4%
7=	Long waiting lists to access physical health services (e.g., long waiting time to access diagnostic, generalised, and specialised services)	13%	13%	0%
7=	Services are too expensive to access (e.g., challenges accessing NDIS funding, insufficient Medicare rebates)	13%	13%	0%
7=	Challenges accessing sufficient funding to support physical health (e.g., Medicare support; bulk-billing services; NDIS funding)	13%	7%	<u>6%</u>
7=	Adjustments or accommodations not offered, or system not taking into account needs or preferences of Autistic people (e.g., appointments or therapies not autism-friendly; options for appointments [telehealth or in person]; and the process of arranging appointments or communicating with staff outside of appointments)	13%	15%	-2%

3.4.1.1.2 Factors causing the problems experienced by Autistic people in relation to physical health services, as reported by Autistic people from low socio-economic backgrounds

A total of 28 Autistic people who are from low socio-economic backgrounds opted to answer this open-ended question on physical health services. Table 38 ranks the nine most commonly reported factors that respondents felt were causing the problems that Autistic people experience in relation to physical health services reported above.

Table 38: Most frequently reported causes of the problems experienced by Autistic people in relation to physical health services, as reported by Autistic people who are from low socio-economic backgrounds

Rank	Causes of the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic people who are from low socio-economic backgrounds <i>n</i> = 28	Entire Autistic sample <i>n</i> = 216	% difference
1=	Staff in health care settings (including administrative settings) have a lack of knowledge or understanding of autism/ neurodiversity, diversity of presentations, and how autism/neurodivergence may impact physical health needs or symptoms, such as pain (e.g., lack of understanding individual needs; lack of understanding of autism; outdated knowledge)	32%	32%	0%
1=	Lack of funding/resources and/or difficulty accessing these supports (including the high costs of health care) (e.g., very expensive; funding shortfall; limited bulk-billing services)	32%	18%	<u>14%</u>
3=	Lack of funding for autism education, training, and upskilling of physical health care professionals (e.g., lack of training within undergraduate and postgraduate level; insufficient ongoing professional development and Autistic-led training)	21%	26%	<u>-5%</u>
3=	Neurotypical/majority needs prioritised, ableism, and lack of neurodiversity-affirming practice (e.g., services are not designed to be inclusive of Autistic people; there is an emphasis on the needs of the practitioner and non-Autistic clients)	21%	13%	<u>8%</u>

Rank	Causes of the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic people who are from low socio-economic backgrounds <i>n</i> = 28	Entire Autistic sample <i>n</i> = 216	% difference
5	Lack of government support and guidance (e.g., a lack of autism-specific research; lack of guidelines/policy; increased red tape and bureaucracy)	18%	10%	<u>8%</u>
6=	Health professionals' reluctance to adapt practices or provide accommodations/supports for Autistic individuals' or to see Autistic clients (e.g., inflexibility; refusal to see Autistic clients)	14%	7%	<u>7%</u>
6=	Dismissing or excluding an Autistic person or their family (e.g., lack of questioning; ignoring symptoms and health concerns)	14%	8%	<u>6%</u>
6=	Health care professionals demonstrating a lack of understanding, empathy, patience, care, and acceptance for Autistic people (e.g., professionals showing discrimination and stereotyping of autism)	14%	13%	1%
7=	Insufficient number of available health care professionals (e.g., lack of professionals entering the field; lack of staff retention and incentives; a lack of university placements to train new professionals)	11%	10%	1%

3.4.1.1.3 Factors that could prevent or reduce the problems experienced by Autistic people in relation to physical health services, as reported by Autistic people from low socio-economic backgrounds

A total of 26 Autistic people from low socio-economic backgrounds opted to answer this open-ended question on physical health services. Table 39 ranks the eight most commonly reported factors that Autistic people from low socio-economic backgrounds reported could prevent or reduce the problems that Autistic people experience in relation to accessing physical health services reported above.

Table 39: Most frequently reported factors that could prevent or reduce the problems experienced by Autistic people in relation to physical health services, as reported by Autistic people who are from low socio-economic backgrounds

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic people who are from low socio-economic backgrounds <i>n</i> = 26	Entire Autistic sample <i>n</i> = 210	% difference
1	Increase (access to) education, training, and upskilling programs for health care professionals and administrative staff about autism, characteristics, and health impacts (e.g., mandatory onboarding; Autistic informed/delivered training; and university level training)	54%	51%	3%
2	Government reform, support, and guidance (e.g., investment in research and services; guidelines, policy and regulations)	31%	14%	17%
3	Increase funding/resources and/or affordability of health services across the lifespan (e.g., increasing access to funding; increasing bulk-billing services; reviewing funding systems such as NDIS)	27%	17%	10%
4=	Increase access and use of physical health care services for Autistic people and their families through the provision of accommodations, flexible access options, and supports (e.g., increased flexibility; and increased access to supports)	19%	14%	5%
4=	Enhance the therapeutic skills and awareness of health care professionals to support their work with Autistic clients (e.g., acceptance; showing empathy and patience)	19%	12%	7%

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic people who are from low socio-economic backgrounds <i>n</i> = 26	Entire Autistic sample <i>n</i> = 210	% difference
6=	Increase the number of health care professionals and health services available (e.g., incentives to increase rural/regional service; broadening scope of practice for health professionals)	12%	13%	-1%
6=	Increase communication options to improve access to health care and access to information about health care (e.g., web-based booking systems; text-based communication; opting in or out of telehealth [i.e., not assuming it is preferred or unpreferred])	12%	17%	<u>-5%</u>
6=	Reducing the cost of health care services (including medications, diagnosis and health care programs) (e.g., Medicare rebates for autism assessments; access to free programs and services)	12%	6%	<u>6%</u>

3.4.1.1.4 Factors that are working well, or have worked well, for Autistic people in relation to physical health services, as reported by Autistic people from low socio-economic backgrounds

Overall, 19 Autistic people from low socio-economic backgrounds replied to this open-ended question. Table 40 ranks the seven most frequently reported factors that Autistic people who are from low socio-economic backgrounds reported to be working well, or that have worked well, for Autistic people in relation to physical health.

Table 40: Most frequently reported problems that Autistic people experience in relation to mental health services, as reported by Autistic people from low socio-economic backgrounds

Rank	What is working well, or has worked well, in relation to Autistic people's experiences with physical health services	% who stated this answer		
		Autistic people who are from low socio-economic backgrounds <i>n</i> = 19	Entire Autistic sample <i>n</i> = 161	% difference
1	Nothing/not a lot	42%	28%	15%
2	When you find the right physical health provider for you, who was often described as knowledgeable about autism, understanding, caring, patient, and non-judgemental (e.g., compassionate; gentle; empathetic)	21%	21%	0%
3=	When there is increased access to autism-informed health professionals and services (e.g., Autistic-led services; services that have expertise in autism)	11%	8%	3%
3=	Health care providers having an awareness and knowledge of autism, the characteristics of autism (including sensory needs), and different presentations (including the presentation of autism in women or girls) (e.g., autism trained and experienced health care professionals; awareness of diversity in pain presentation)	11%	6%	5%
3=	When providers ask questions and listen to Autistic people and/or their family members, and include Autistic individuals and their families in health care decisions (e.g., open communication; respectful practice; seeking consent, preferences and opinions)	11%	8%	3%

Rank	What is working well, or has worked well, in relation to Autistic people's experiences with physical health services	% who stated this answer		
		Autistic people who are from low socio-economic backgrounds <i>n</i> = 19	Entire Autistic sample <i>n</i> = 161	% difference
3=	Increased and comprehensive diagnosis of autism and data provided to inform support (e.g., early diagnosis; comprehensive assessments)	11%	2%	<u>9%</u>
3=	When there are increased communication options to improve access to, and information about, health care (e.g., web-based booking systems; option of telehealth; non-verbal communication options)	11%	12%	-1%

3.4.1.2 Autism Connect dataset: Contacts relating to physical health

The Autism Connect dataset did not contain any contacts relating to physical health where it was possible to identify that the Autistic people was from a low socio-economic background, so this cannot be reported. This highlights a clear need to work with this community to extend knowledge on this issue.

3.4.1.3 “Barriers to care” questionnaire

A total of 19 people from families from low socio-economic backgrounds (pre-tax family income below \$45,000), responded to the questionnaire that asked them to rank predetermined statements relating to barriers to accessing acute physical health care. The five barriers on the “Barriers to care” questionnaire with the highest mean scores (i.e., happen most frequently) for Autistic children who are from low socio-economic backgrounds are represented in Table 41. Where there was a difference of 0.25 or more between parent ratings for Autistic children who are from low socio-economic backgrounds and all Autistic children, the score difference is highlighted with bold and underlined text in the tables.

It is important to consider the small sample size ($n < 20$) for this priority group when interpreting the results.

Table 41: Five highest scoring barriers to acute physical health care on the “Barriers to care” questionnaire as reported by parents of Autistic children who are from low socio-economic backgrounds

“Barriers to care” questionnaire Question	Mean (SD) Autistic children who are from low socio-economic backgrounds <i>n</i> = 19	Mean (SD) entire sample <i>N</i> = 107	Score difference for Autistic children who are from low socio-economic backgrounds
Meeting the needs of other family members	4.00 (1.45)	3.39 (1.50)	<u>0.61</u>
Having to wait too long in the waiting room	4.26 (1.20)	3.96 (1.30)	<u>0.30</u>
Getting care after hours or on the weekends	4.05 (1.27)	3.47 (1.54)	<u>0.58</u>
Getting hold of the doctor	4.11 (1.20)	3.86 (1.32)	<u>0.25</u>
Getting a thorough examination	3.95 (1.43)	3.62 (1.33)	<u>0.33</u>

The five barriers on the “Barriers to care” questionnaire with the lowest mean scores (i.e., happen least frequently) for Autistic children who are from low socio-economic backgrounds are represented in Table 42.

Table 42: Five lowest scoring barriers to acute physical health care on the “Barriers to care” questionnaire, as reported by parents of Autistic children who are from low socio-economic backgrounds

“Barriers to care” questionnaire Question	Mean (SD) Autistic children who are from low socio-economic backgrounds <i>n</i> = 19	Mean (SD) entire sample <i>N</i> = 107	Score difference for Autistic children who are from low socio-economic backgrounds
Doctors not believing in home or traditional remedies	1.47 (0.84)	1.70 (1.26)	-0.23
Doctors or nurses not fluent in your language	1.63 (1.26)	1.41 (.98)	0.22
Understanding doctors’ orders	1.74 (1.10)	1.54 (.91)	0.20
Getting enough help with paperwork or forms	1.89 (1.45)	1.70 (1.19)	0.19
Being judged on your appearance, your ancestry, or your accent	1.95 (1.43)	1.93 (1.33)	0.02

3.4.2 Mental health services

3.4.2.1 The “1,000 insights” community views survey mental health services

A total of 32 Autistic people who are from low socio-economic backgrounds (including $n = 21$ Autistic people who consider themselves poor, and $n = 11$ Autistic people who consider themselves very poor) answered at least one of the four open-ended questions on mental health services. These four questions were:

- What are three problems that Autistic people experience when using, or trying to access, mental health services?
- What do you think is causing these problems?
- What do you think could prevent or reduce these problems?
- What is working well, or has worked well, for Autistic people when using or trying to access mental health services?

The most frequently reported responses to each of the open-ended questions are reported within this section. The tables include the proportion of Autistic people from low socio-economic backgrounds who provided a response that was coded into this category (with examples of the responses coded into this category) alongside the proportion of all Autistic people who provided a response that was coded into this category. Where there was a difference of 5% or more between Autistic people who are from low socio-economic backgrounds and all Autistic people, the percentage difference is highlighted with bold and underlined text in the tables.

3.4.2.1.1 Problems experienced by Autistic people in relation to mental health services, as reported by Autistic people from low socio-economic backgrounds

A total of 31 Autistic people from low socio-economic backgrounds opted to answer this open-ended question in relation to mental health services. Table 43 ranks the 11 problems that Autistic people who are from low socio-economic backgrounds most frequently reported Autistic people experiencing in relation to mental health services (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 43: Most frequently reported problems that Autistic people experience in relation to mental health services, as reported by Autistic people from low socio-economic backgrounds

Rank	Problems experienced by Autistic people in relation to mental health services	% who stated this answer		
		Autistic respondents from low socio-economic backgrounds <i>n</i> = 31	Entire Autistic sample <i>n</i> = 250	% difference
1=	Prohibitive cost (e.g., very expensive; services able to charge too much)	29%	28%	1%
1=	Insufficient availability/access of relevant, skilled mental health worker (e.g., lack of providers who can do assessments; challenges finding neurodivergent therapist)	29%	18%	11%
1=	Misdiagnosis of autism and/or co-occurring conditions (e.g., misdiagnosing autism as, for example, a personality disorder; diagnostic overshadowing)	29%	12%	17%
4=	Lack of knowledge or understanding of autism/neurodiversity, its presentation, and its impact across the lifespan (e.g., lack of knowledge about autism in females; lack of understanding of lived experience)	19%	28%	-9%
4=	Long or closed waitlists (e.g. long waiting time to access diagnostic services, psychologists, and psychiatrists; waiting lists exacerbate issues)	19%	19%	0%

Rank	Problems experienced by Autistic people in relation to mental health services	% who stated this answer		
		Autistic respondents from low socio-economic backgrounds <i>n</i> = 31	Entire Autistic sample <i>n</i> = 250	% difference
4=	Professionals may make assumptions or have pre-conceived ideas of autism, holding a deficit-based view (e.g., stereotyping; behaviours viewed as attention seeking)	19%	10%	<u>9%</u>
4=	Trivialising or not believing someone's autism diagnosis or their lived experience (e.g. not believing someone's experience)	19%	10%	<u>9%</u>
8	Strategies not tailored for the individual client or neurodivergent people (e.g., not tailored for individual needs or preferred goals; neurotypical strategies do not always work for Autistic people)	13%	10%	3%
9=	Insufficient availability/access of appropriate services (e.g., lack of services specialising in autism; long distance to travel)	10%	17%	<u>-7%</u>
9=	Lack of knowledge or understanding of the interaction between autism and co-occurring conditions including mental health problems (e.g., lack of knowledge of mental health issues and experiences for Autistic people; lack of understanding of co-occurring conditions including ADHD and mental health)	10%	6%	4%
9=	Mental health services are not designed for/inclusive of Autistic individuals (e.g., does not support neurodivergent people; designed for people with only mental health conditions; not suitable)	10%	3%	<u>7%</u>

3.4.2.1.2 Factors causing the problems experienced by Autistic people in relation to mental health services, as reported by Autistic people from low socio-economic backgrounds

A total of 28 Autistic people who are from low socio-economic backgrounds opted to answer this open-ended question on mental health services. Table 44 ranks the most commonly reported factors that Autistic people who are from low socio-economic backgrounds felt were causing the problems that Autistic people experience in relation to mental health services reported above. The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 44: Most frequently reported causes of the problems experienced by Autistic people in relation to mental health services, as reported by Autistic people from low socio-economic backgrounds

Rank	Causes of the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic people who are from low socio-economic backgrounds <i>n</i> = 28	Entire Autistic sample <i>n</i> = 213	% difference
1	Concern about therapeutic skills and/or attitude (e.g., lack of respect; ableism; not allowing time to develop relationship; ignorance)	32%	17%	15%
2=	Lack of knowledge or understanding of autism and neurodivergent conditions, its presentation, and its impact (e.g., lack of understanding the heterogeneous presentation of autism; lack of understanding of stresses associated with autism)	29%	28%	1%
2=	Lack of, or poor quality of, training for mental health professionals (e.g., poor training; lack of training in diagnosing and treating autism appropriately)	29%	27%	2%
4	Insufficient funding (generally) (e.g., lack of funding; funding shortfall)	14%	15%	-1%
5=	Insufficient number of professionals with an interest/expertise in autism (e.g., lack of qualified people specialising in autism; lack of specialists in rural areas)	11%	12%	-1%

Rank	Causes of the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic people who are from low socio-economic backgrounds <i>n</i> = 28	Entire Autistic sample <i>n</i> = 213	% difference
5=	Impact of decisions made by the government (e.g., government policies; government cuts; poor management of mental health services)	11%	10%	1%
5=	Strategies and practices considered insufficient, inappropriate, or poor quality (e.g., lack of awareness of how to modify practices; neuro-normative concepts of well-being applied to Autistic people)	11%	9%	2%
5=	The system is challenging and is not designed to support the access/use of Autistic people (e.g., inflexible; access needs are not enquired about)	11%	6%	5%
5=	Approaches currently focus on medical model rather than more inclusive approaches (e.g., medical model is a problem; interaction with society is the problem, not autism)	11%	6%	5%
10=	Overwhelmed system/professionals with insufficient resources (e.g., lack of resources; overwhelmed staff; time pressure)	7%	7%	0%
10=	Lack of knowledge, understanding, or experience of co-occurring conditions including mental health, and their interaction with autism (e.g., lack of knowledge about, or experience with, mental health conditions, Autistic burnout)	7%	7%	0%
10=	Insufficient number of, or access to, services (e.g., lack of services/facilities; gatekeeping; distance for rural people)	7%	6%	1%

3.4.2.1.3 Factors that could prevent or reduce the problems experienced by Autistic people in relation to mental health services, as reported by Autistic people from low socio-economic backgrounds

A total of 23 Autistic people who are from low socio-economic backgrounds opted to answer this open-ended question on mental health services. Table 45 ranks the 10 most frequently reported factors that Autistic people who are from low socio-economic backgrounds reported could prevent or reduce the problems that Autistic people experience in relation to accessing mental health services reported above. The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 45: Most frequently reported factors that could prevent or reduce the problems experienced by Autistic people accessing mental health services, as reported by Autistic people from low socio-economic backgrounds

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic people who are from low socio-economic backgrounds <i>n</i> = 23	Entire Autistic sample <i>n</i> = 199	% difference
1	Increase (access to) training for people working as mental health professionals to enhance their understanding of autism (and other neurodivergence), including training from Autistic people with lived experience (e.g., mandatory, regular training; Autistic informed/delivered training)	61%	46%	15%
2	Increase funding and/or affordability of mental health services across the lifespan (e.g., government funded functional capacity assessment; price caps and/or rebates)	17%	19%	-2%
3=	More mental health professionals, including those specialising in autism, and those who are Autistic/neurodivergent themselves (e.g., more doctors; more psychologists; create new roles and professions to support Autistic people; incentives for experts; alternative qualification pathways)	13%	19%	-6%
3=	Make access and use of services easier and more autism-friendly (e.g., alternative methods to book appointments, increased flexibility of appointments; environment)	13%	10%	3%

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic people who are from low socio-economic backgrounds <i>n</i> = 23	Entire Autistic sample <i>n</i> = 199	% difference
5=	Facilitate changes to practice to focus on strengths, neurodiversity-affirming care, and skills relevant to supporting Autistic people (e.g., use social model rather than medical model; neurodiversity-affirming practice)	9%	10%	-1%
5=	Improve access to, and quality of, services (e.g., reduce the red tape; consideration of access for regional and rural areas; services for people with complex needs)	9%	9%	0%
5=	Enhance the quality of university education and number of places available (e.g., do not phase out psychology general registration pathway; provide education on neurodiversity-affirming practice; include information on co-occurring intellectual disability and other co-occurring conditions)	9%	9%	0%
5=	Education to support general public's understanding of autism (e.g., address stigma; publicity drives to debunk myths and attitudes)	9%	7%	2%
5=	More co-produced research that provides evidence-based practices for neurodivergent people (e.g., include Autistic and neurodivergent people in research design; research needed into neuro-affirmative practice)	9%	7%	2%
5=	Government reform and support of mental health sector (e.g., legislation around language use; better legislation for protecting clients against poor treatment)	9%	7%	2%

3.4.2.1.4 Factors that are working well, or have worked well, for Autistic people in relation to mental health services, as reported by Autistic people from low socio-economic backgrounds

A total of 20 Autistic people who are from low socio-economic backgrounds opted to answer this open-ended question on mental health services. Table 46 ranks the six most commonly reported factors that Autistic people who are from low socio-economic backgrounds reported to be working well, or that have worked well, for Autistic people in relation to mental health. The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 46: Most frequently reported factors that are working well, or have worked well, for Autistic people in relation to mental health services, as reported by Autistic people from low socio-economic backgrounds

Rank	What is working well, or has worked well, in relation to Autistic people’s experiences with mental health services	% who stated this answer		
		Autistic people who are from low socio-economic backgrounds <i>n</i> = 20	Entire Autistic sample <i>n</i> = 155	% difference
1	Nothing/not a lot	50%	25%	<u>25%</u>
2	Support from family, friends, and Autistic/neurodivergent community (e.g., parent advocacy; ability to bring trusted person to appointments; social groups to meet other Autistic people)	20%	8%	<u>12%</u>
3	When alternative/flexible access are available (inc. making appointment and practice) (e.g., online chat services; alternative booking options such as leaving voice message or online portal)	15%	13%	2%
4	Understanding what is best for oneself and advocating for this (e.g., creating environments where Autistic people feel safe; finding a therapist who works for the individual; mental health services that give Autistic people agency, choice and empowerment; self-advocacy)	10%	4%	<u>6%</u>
5=	When you find the right mental health professional for you, who is often knowledgeable/experienced about autism and its associated needs (e.g., understands autism and neurodiversity; experience working with Autistic people)	5%	18%	<u>-13%</u>
5=	When NDIS funding has been provided to support needs (e.g., NDIS can reduce mental health challenges when all needs are covered; supportive NDIS plan manager)	5%	13%	<u>-8%</u>

3.4.2.2 Autism Connect dataset: Contacts relating to mental health

Only three contacts to Autism Connect which referred to mental health-related issues could be classified as relating specifically to Autistic people who are from low socio-economic backgrounds. This is not a sufficient number of contacts from which to draw conclusions, so the data are not reported here. This highlights a clear need to work with this community to extend knowledge on this issue.

3.4.2.3 “Making therapy better” questionnaire

Socioeconomic position was not collected as part of this dataset so data cannot be extracted for this priority group. This highlights a clear need to work with this community to extend knowledge on this issue.

3.4.3 Summary of existing data for Autistic people from low socio-economic backgrounds

3.4.3.1 Summary of differences noted in the data for Autistic people from low socio-economic backgrounds as compared to the data for the entire Autistic sample

The focus in this section is on any items that differed within datasets provided by, or in relation to, Autistic people from low socio-economic backgrounds and the data for the entire Autistic sample. A general summary of the issues with health and mental health services raised by, or in relation to, Autistic people from low socio-economic backgrounds is provided in Section 3.4.3.2.

When the physical and mental health care service experiences of Autistic people who are from low socio-economic backgrounds were compared to the entire sample of Autistic people in this study, there were **42 areas in which they differed substantially**: 25 related to physical health care service experiences and 17 related to mental health care service experiences (see Figure 6, Figure 7, and Figure 8). The definitions used and process to calculate substantial differences are documented in the methods chapter.

This large number of substantial differences highlights the importance of considering intersectionality when exploring physical and mental health care experiences of Autistic people. The items where data provided by, or in relation to, Autistic people from low socio-economic backgrounds highlighted a substantial difference from the entire sample of Autistic people predominantly focused upon problems or challenges with therapist skills and the provision of accommodations and adaptations, pragmatics and practicalities (e.g. care for other family members), funding, being believed, and a reliance on the medical model/not receiving neurodiversity-affirming care. Twice as many Autistic people from low socio-economic backgrounds said that “nothing” is working well for Autistic people who access mental health care services.

Figure 6: Summary of substantial differences in existing datasets reporting on physical health service experiences for Autistic people from low socio-economic backgrounds

In relation to mental health services, Autistic people from rural, regional and remote backgrounds, or their parents/caregivers, were more likely to...

- ▲ Report health professionals' reluctance to adapt practices or provide accommodations/supports for Autistic individuals as a problem (+17%; "1,000 insights" survey).
- ▲ Report challenges meeting the needs of other family members as a high scoring barrier to acute physical health care (+0.61; "Barriers to care" questionnaire).
- ▲ Report government reform, support, and guidance could reduce problems (+17%; "1,000 insights" survey).
- ▲ Report that nothing/not a lot is working well or has worked well (+15%; "1,000 insights" survey).
- ▲ Rate challenges getting care after hours or on the weekends as a high scoring barrier to acute physical health care (+0.58; "Barriers to care" questionnaire).
- ▲ Report that lack of funding/resources and/or difficulty accessing these supports (including high costs of health care) as a cause of problems (+14%; "1,000 insights" survey).
- ▲ Report that increasing funding/resources and/or affordability of health services across the lifespan could reduce problems (+10%; "1,000 insights" survey).
- ▲ Report professionals' therapeutic skills as a problem (+9%; "1,000 insights" survey).
- ▲ Rate challenges getting a thorough examination as a high scoring barrier to acute physical health care (+0.33; "Barriers to care" questionnaire).
- ▲ Report increased and comprehensive diagnosis of autism and data provided to inform support as working/having worked (+9%; "1,000 insights" survey).
- ▲ Report neurotypical/majority needs being prioritised, ableism, and lack of neurodiversity affirming practice as a cause of problems (+8%; "1,000 insights" survey).
- ▲ Report lack of government support and guidance as a cause of problems (+8%; "1,000 insights" survey).
- ▲ Report health professionals' reluctance to adapt practices or provide accommodations/supports for Autistic individuals' or to see Autistic clients as a cause of problems (+7%; "1,000 insights" survey).
- ▲ Rate having to wait too long in the waiting room as a high scoring barrier to acute physical health care (+0.30; "Barriers to care" questionnaire).
- ▲ Report the process to access and physically attend health services as a problem (+7%; "1,000 insights" survey).
- ▲ Report that enhancing therapeutic skills and awareness of health care professionals to support their work with Autistic clients could reduce problems (+7%; "1,000 insights" survey).
- ▲ Report dismissing or excluding an Autistic person or their family (+6%; "1,000 insights" survey).
- ▲ Report challenges accessing sufficient funding to support physical health as a problem (+6%; "1,000 insights" survey).
- ▲ Report that reducing the cost of health care services (including medications, diagnosis and health care programs) could reduce problems (+6%; "1,000 insights" survey).
- ▲ Rate challenges getting hold of the doctor as a high scoring barrier to acute physical health

care (+0.25; “Barriers to care” questionnaire).

- ▲ Report physical health care providers dismissing or not believing the reports of Autistic people or their family members (including not believing a person is Autistic) as a problem (+5%; “1,000 insights” survey).
 - ▲ Report that increasing access and use of physical health care services for Autistic people and their families through the provision of accommodation, flexible access options, and supports, could reduce problems (+5%; “1,000 insights” survey).
 - ▲ Report that health care providers having an awareness and knowledge of autism, the characteristics of autism (including sensory needs), and different presentations (including the presentations of autism in women or girls) as working/having worked (+5%; “1,000 insights” survey).
-

Figure 7: Summary of substantial differences in existing datasets reporting on physical health service experiences for Autistic people from low socio-economic backgrounds

In relation to physical health services, Autistic people from low socio-economic backgrounds were less likely to...

- ▼ Report lack of funding for autism education, training, and upskilling of physical health professionals as a cause of a problem (-5%; “1,000 insights” survey).
 - ▼ Report that increasing communication to improve access to health care and access to information about health care could reduce problems (-5%; “1,000 insights” survey).
-

Figure 8: Summary of substantial differences in existing datasets reporting on mental health service experiences for Autistic people from low socio-economic backgrounds

In relation to mental health services, Autistic people from low socio-economic backgrounds were more likely to...

- ▲ Report that nothing/not a lot is working well or has worked well (+25%; “1,000 insights” survey).
- ▲ Report misdiagnosis of autism and/or co-occurring conditions as a problem (+17%; “1,000 insights” survey).
- ▲ Report that increasing (access to) training for people working as mental health professionals to enhance their understanding of autism (and other neurodivergence), including training from Autistic people with lived experience, can reduce problems (+15%; “1,000 insights” survey).
- ▲ Report that concern about therapeutic skills and/or attitude is causing the problems (+15%; “1,000 insights” survey).
- ▲ Report that support from family, friends, and Autistic/neurodivergent community is working/has worked well (+12%; “1,000 insights” survey).
- ▲ Report Insufficient availability/access of relevant, skilled mental health worker as a problem (+11%; “1,000 insights” survey).
- ▲ Report professionals making assumptions of having pre-conceived ideas of autism, holding a deficit-based view as a problem (+9%; “1,000 insights” survey).
- ▲ Report trivialising or not believing someone’s autism diagnosis or their lived experiences as a problem (+9%; “1,000 insights” survey).
- ▲ Report mental health services not being designed for/inclusive of Autistic individuals as a problem (+7%; “1,000 insights” survey).
- ▲ Report understanding what is best for oneself and advocating for this as working/having worked well (+6%; “1,000 insights” survey).
- ▲ Report that the challenging system, that is not designed to support the access/use of Autistic people, is causing the problems (+5%; “1,000 insights” survey).
- ▲ Report that the current focus on the medical model, rather than more inclusive approaches, is causing the problems (+5%; “1,000 insights” survey).

In relation to mental health services, Autistic people from low socio-economic backgrounds were less likely to...

- ▼ Report that increasing the number of mental health professionals, including those specialising in autism and those who are Autistic/neurodivergent themselves, can reduce problems (-6%, “1,000 insights” survey).
 - ▼ Report insufficient availability/access of appropriate services as a problem (-7%; “1,000 insights” survey).
 - ▼ Report that NDIS funding being provided to support needs is something that is working/has worked well (-8%; “1,000 insights” survey).
 - ▼ Report lack of knowledge or understanding of autism/neurodiversity, its presentation, and its impact across the lifespan as a problem (-9%; “1,000 insights” survey).
 - ▼ Report that finding the right mental health professional for you, who is often knowledgeable/experienced about autism and its associated needs, is working/has worked well (-13%; “1,000 insights” survey).
-

3.4.3.2 Summary of issues or experiences with physical and/or mental health services for Autistic people from low socio-economic backgrounds as reported in the four datasets

The issues and experiences within physical health and mental health services have been described individually above. This section highlighting areas that were identified across both physical health and mental health services for Autistic people from low socio-economic backgrounds.

The data reflect information gathered in multiple ways: (a) open text answers to a survey, (b) rating level of agreement on a rating scale, and (c) contacting the Autism Connect helpline. Despite these differences in how the data were obtained, commonalities were identified across the physical and mental health service domains. These commonalities are discussed below. It is important, however, that we also take the time to consider the responses unique to each individual domain or dataset as these provide critical insights into the challenges experienced within a specific service.

Factors common across physical and mental health services: Commonalities in the problems identified by Autistic people from low socio-economic backgrounds across the physical and mental health service domains include:

- (a) professionals holding a **limited knowledge of autism** and its presentation
- (b) the **reluctance of professionals to adapt practices/strategies** or accommodations to support Autistic people
- (c) professionals **dismissing or not believing** the experiences of Autistic people
- (d) practical, pragmatic and financial **challenges accessing** services
- (e) large or prohibitive **costs** associated with the service
- (f) **poor clinical decisions**, including misdiagnosis of autism and co-occurring conditions, and
- (g) **long or closed waitlists** to access these services.

The first five themes (a to e) reported above were echoed in both what Autistic people from low socio-economic backgrounds perceive to be the causes of these problems, and strategies that could be used to reduce them. Specifically, to support providers to increase their knowledge of autism, Autistic people advocate for an increase in the access to, and quality of, **autism training courses**. The increase in knowledge resulting from these courses could assist providers in **tailoring their strategies and approaches** to be appropriate for Autistic individuals; increasing practitioner's **awareness of neurodiversity-affirming** approaches; and **enhancing their therapeutic skills** when working with Autistic individuals. This increase in autism knowledge could also enable services to put in place methods to support Autistic people to **access and use these services** (e.g., booking online, increased communication options, provision of service information ahead of time). Finally, Autistic people from low socio-economic backgrounds advocate for ways to **financially support access** to these services, whether by reducing the cost of the services or increasing access to funding across the lifespan (e.g., Medicare, NDIS).

A further factor that was raised by, or in relation to, Autistic people from low socio-economic backgrounds was the need for **additional health care providers, including those with expertise in autism and/or lived experience**. Having these additional, knowledgeable practitioners could improve access to these important mental and physical health services.

3.4.4 Summary

A large number ($n = 42$) of substantial differences were observed between the experiences of Autistic people from low socio-economic backgrounds and the entire sample of Autistic people within the datasets. This underscores the importance of this research, and of working with Autistic people within this priority group to better understand experiences due to intersectionality and ways to better support access to, and use of, physical and mental health care services within Australia. This need is further emphasised given that only a relatively small number of respondents from these large datasets were identified as having a low socio-economic background. Deeper consultations with this group will help us to understand the impact of these differences on the health and mental health outcomes Autistic people from low socio-economic backgrounds.

That we found commonalities across the physical and mental health service domains highlights the robust nature of these challenges experienced by Autistic people from low socio-economic backgrounds. These commonalities provide ideal starting points for improvements to these service domains that could be beneficial for Autistic people from low socio-economic backgrounds in Australia.

It is important to note that it was not possible to identify those from low socio-economic backgrounds within some of the pre-existing datasets enquired. Future work should ensure that these data are consistently collected, so as to allow for a better understanding of the experiences of Autistic people within this priority group to be obtained.

3.5 Autistic people who are culturally and linguistically diverse

3.5.1 Physical health services

3.5.1.1 The “1,000 insights” community views survey physical health services

A total of 19 Autistic people who identify as culturally and linguistically diverse (CALD) answered at least one of the four open-ended questions on physical health services. These questions were:

- What are three problems that Autistic people experience when accessing, or trying to access, physical health services?
- What do you think is causing these problems?
- What do you think could prevent or reduce these problems?
- What is working well, or has worked well, for Autistic people in relation to physical health care services?

The most frequently reported responses to each of the questions are reported within this section. The tables include the proportion of Autistic CALD people who provided a response that was coded into this category (with examples of the responses coded into this category) alongside the proportion of all Autistic people who provided a response that was coded into this category. Where there was a difference of 5% or more between Autistic CALD people and all Autistic people, the percentage difference is highlighted with bold and underlined text in the tables.

It is important to consider the small sample size ($n < 20$) for this priority group when interpreting the results in the following sections.

3.5.1.1.1 Problems experienced by Autistic people in relation to physical health services, as reported by Autistic people who are culturally and linguistically diverse

A total of 18 Autistic CALD people opted to answer this open-ended question in relation to physical health services. Table 47 ranks the 11 problems that Autistic CALD people most frequently reported Autistic people experiencing in relation to physical health services (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 47: Most frequently reported problems experienced by Autistic people in relation to physical health services, as reported by Autistic culturally and linguistically diverse people

Rank	Problems experienced by Autistic people in relation to physical health services	% who stated this answer		
		Autistic culturally and linguistically diverse people <i>n</i> = 18	Entire Autistic sample <i>n</i> = 253	% difference
1=	Concerns about professional’s therapeutic skills (e.g., lack of patience, empathy, care or understanding; mistreatment)	33%	16%	<u>17%</u>
1=	Physical health care providers dismissing or not believing the reports of Autistic people or their family members (including not believing a person is Autistic) (e.g., dismissing symptoms or requests)	33%	26%	<u>7%</u>
3=	Staff in health care settings (providers and administrative staff) have a poor understanding or knowledge of autism, how it presents in different people or contexts, and how it impacts the experience of health care settings (e.g., outdated knowledge of autism; lack of knowledge of how autism impacts the experience of health care settings)	22%	23%	-1%
3=	Health professionals’ reluctance to adapt practices or provide accommodations/supports for Autistic individuals (e.g., inflexibility, one-size-fits-all, lack of neurodiversity-affirming care)	22%	17%	<u>5%</u>

Rank	Problems experienced by Autistic people in relation to physical health services	% who stated this answer		
		Autistic culturally and linguistically diverse people <i>n</i> = 18	Entire Autistic sample <i>n</i> = 253	% difference
5	Adjustments or accommodations not offered, or system not taking into account needs or preferences of Autistic people (e.g., appointments or therapies not autism-friendly; options for appointments [telehealth or in person]; and the process of arranging appointments or communicating with staff outside of appointments)	17%	15%	2%
6=	Lack of knowledge on atypical presentations (including pain and masking) and treatment of health problems in Autistic people (e.g., lack of understanding about the diversity of sensory responses, presentation of characteristics in Autistic women and girls, and mental health needs of Autistic people)	11%	15%	-4%
6=	Poor clinical decisions (e.g., misdiagnosing, reactive not preventative focus)	11%	9%	2%
6=	Difficulties with the process to access and physically attend health services (e.g., organising and understanding forms, service availability/options, paperwork and appointments; transport)	11%	12%	-1%
6=	Services are too expensive to access (e.g., challenges accessing NDIS funding, insufficient Medicare rebates)	11%	13%	-2%
6=	The sensory elements of physical health services or settings (including waiting rooms and emergency departments) are not supportive for Autistic people, sometimes leading to sensory overwhelm (e.g., crowded, bright and noisy waiting rooms)	11%	19%	<u>-8%</u>
6=	Autistic characteristics and co-occurring conditions impacting access/use of services (e.g., executive functioning skills; interoception)	11%	8%	3%

3.5.1.1.2 Factors causing the problems experienced by Autistic people in relation to physical health services, as reported by Autistic people who are culturally and linguistically diverse

A total of 13 Autistic CALD people opted to answer this open-ended question on physical health services. Table 48 ranks the six most commonly reported factors that respondents felt were causing the problems that Autistic people experience in relation to physical health services reported above.

Table 48: Most frequently reported causes of the problems experienced by Autistic people in relation to physical health services, as reported by Autistic culturally and linguistically diverse people

Rank	Causes of the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic culturally and linguistically diverse people <i>n</i> = 13	Entire Autistic sample <i>n</i> = 213	% difference
1	Staff in health care settings (including administrative settings) have a lack of knowledge or understanding of autism/ neurodiversity, diversity of presentations, and how autism/neurodivergence may impact physical health needs or symptom, such as pain (e.g., lack of understanding individual needs; lack of understanding of autism; outdated knowledge)	31%	32%	-1%
2=	Lack of funding for autism education, training, and upskilling of physical health care professionals (e.g., lack of training within undergraduate and postgraduate level; insufficient ongoing professional development and Autistic-led training)	23%	26%	-3%
2=	Neurotypical/majority needs prioritised, ableism, and lack of neurodiversity-affirming practice (e.g., services are not designed to be inclusive of Autistic people; there is an emphasis on the needs of the practitioner and non-Autistic clients)	23%	13%	10%
4=	Health care professionals demonstrating a lack of understanding, empathy, patience, care, and acceptance for Autistic people (e.g., professionals showing discrimination and stereotyping of autism)	15%	13%	2%
4=	Lack of individual supports and accommodations (e.g. lack of knowledge of accommodations)	15%	7%	8%

Rank	Causes of the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic culturally and linguistically diverse people <i>n</i> = 13	Entire Autistic sample <i>n</i> = 213	% difference
4=	Dismissing or excluding an Autistic person or their family (e.g., lack of questioning; ignoring symptoms and health concerns)	15%	8%	<u>7%</u>

3.5.1.1.3 Factors that could prevent or reduce the problems experienced by Autistic people in relation to physical health services, as reported by Autistic people who are culturally and linguistically diverse

A total of 13 Autistic CALD people opted to answer this open-ended question on physical health services. Table 49 ranks the 10 most commonly reported factors that Autistic CALD people reported could prevent or reduce the problems that Autistic people experience in relation to accessing physical health services reported above. This sample is small, so caution should be aired when interpreting these results.

Table 49: Most frequently reported factors that could prevent or reduce the problems experienced by Autistic people in relation to physical health services, as reported by Autistic culturally and linguistically diverse people

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic culturally and linguistically diverse people <i>n</i> = 13	Entire Autistic sample <i>n</i> = 210	% difference
1	Increase (access to) education, training, and upskilling programs for health care professionals and administrative staff about autism, characteristics, and health impacts (e.g., mandatory onboarding; Autistic informed/delivered training; and university level training)	31%	51%	<u>-20%</u>
2=	Government reform, support, and guidance (e.g., investment in research and services; guidelines, policy and regulations)	23%	14%	<u>9%</u>
2=	Increase the number of health care professionals and health services available (e.g., incentives to increase rural/regional service; broadening scope of practice for health professionals)	23%	13%	<u>10%</u>
2=	Increase funding/resources and/or affordability of health services across the lifespan (e.g., increasing access to funding; increasing bulk-billing services; reviewing funding systems such as NDIS)	23%	17%	<u>6%</u>
2=	Increase communication options to improve access to health care and access to information about health care (e.g., web-based booking systems; text-based communication; opting in or out of telehealth [i.e., not assuming it is preferred or unpreferred])	23%	17%	<u>6%</u>

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic culturally and linguistically diverse people <i>n</i> = 13	Entire Autistic sample <i>n</i> = 210	% difference
6=	Enhance the therapeutic skills and awareness of health care professionals to support their work with Autistic clients (e.g., acceptance; showing empathy and patience)	15%	12%	3%
6=	Actively employ, consult, and collaborate with neurodivergent practitioners, support workers, advocates, and those in leadership/decision-making roles (e.g., consult with Autistic people when designing or developing services; services actively employing neurodivergent practitioners, support workers, advocates)	15%	10%	5%
8=	Listen, validate and take concerns of Autistic individuals and their families/carers seriously (e.g., asking questions, working in partnership with clients)	8%	9%	-1%
8=	Change the diagnostic criteria for autism and diagnostic processes (e.g. changing the level system)	8%	4%	4%
8=	Create sensory-friendly physical health services or settings, including training to inform health care professionals of how overwhelming these environments can be for Autistic people and the impact this may have on their appointment (e.g., create sensory-friendly waiting rooms and emergency departments)	8%	11%	-3%

3.5.1.1.4 Factors that are working well, or have worked well, for Autistic people in relation to physical health services, as reported by Autistic people who are culturally and linguistically diverse

Overall, 10 Autistic CALD people replied to this open-ended question. Table 50 ranks the nine most commonly reported factors that Autistic CALD people reported to be working well, or that have worked well, for Autistic people in relation to physical health. Again, caution should be aired in interpreting these responses due to the small sample size.

Table 50: Most frequently reported factors that are working well, or have worked well, for Autistic people in relation to physical health services, as reported by Autistic culturally and linguistically diverse people

Rank	What is working well, or has worked well, in relation to Autistic people’s experiences with physical health services	% who stated this answer		
		Autistic culturally and linguistically diverse people <i>n</i> = 10	Entire Autistic sample <i>n</i> = 161	% difference
1	Nothing/not a lot	50%	28%	<u>22%</u>
2	When health care services are affordable and there is access to funding (beyond NDIS) (e.g., Medicare rebates; bulkbilling; and Health Care cards)	20%	6%	<u>14%</u>
3=	When you find the right physical health provider for you, who was often described as knowledgeable about autism, understanding, caring, patient, and non-judgemental (e.g., compassionate; gentle; empathetic)	10%	21%	<u>-11%</u>
3=	When health care providers proactively ask about and provide alternative/flexible access, accommodations, and/or support for Autistic individuals (e.g., longer appointments; more flexibility with appointments; support people attending; home visits)	10%	9%	1%
3=	When providers ask questions and listen to Autistic people and/or their family members, and include Autistic individuals and their families in health care decisions (e.g., open communication; respectful practice; seeking consent, preferences, and opinions)	10%	8%	2%

Rank	What is working well, or has worked well, in relation to Autistic people's experiences with physical health services	% who stated this answer		
		Autistic culturally and linguistically diverse people <i>n</i> = 10	Entire Autistic sample <i>n</i> = 161	% difference
3=	When there is continuity of care and continuity of information across providers (e.g., collaborative health teams; building relationships; individual care plans; accessible health information; health passports)	10%	6%	4%
3=	When Autistic individuals feel supported in using physical health services through the growing autism movement, Autistic advocates, collaboration with Autistic partners and awareness in the community (e.g., support for Autistic people who have been mistreated by medical professionals; autism advocacy groups; public education and information availability)	10%	2%	8%
3=	When there is increased access to autism-informed health professionals and services (e.g., Autistic-led services; services that have expertise in autism)	10%	8%	2%
3=	When NDIS plans and funding are approved for health supports (e.g., helpful NDIS coordinators can improve access to services; reduces financial burden on families)	10%	9%	1%

3.5.1.2 Autism Connect dataset: Contacts relating to physical health

A total of three contacts to Autism Connect referred to physical health-related issues, specifically in relation to Autistic CALD people. This is not a sufficient number of people from whom to draw conclusions, highlighting a clear need to work with this community to extend knowledge on this issue.

3.5.1.3 “Barriers to care” questionnaire

Only seven respondents to the questionnaire that asked them to rank predetermined statements relating to barriers to accessing acute physical health care identified as culturally and linguistically diverse. This is not a sufficient sample size to report upon. This highlights a clear need to work with members of this community to extend knowledge on this issue.

3.5.2 Mental health services

3.5.2.1 The “1,000 insights” community views survey mental health services

A total of 19 Autistic CALD people answered at least one of the four open-ended questions on mental health services. These four questions were:

- What are three problems that Autistic people experience when using, or trying to access, mental health services?
- What do you think is causing these problems?
- What do you think could prevent or reduce these problems?
- What is working well, or has worked well, for Autistic people when using or trying to access mental health services?

The most frequently reported responses to each of the questions are reported within this section. The tables include the proportion of Autistic CALD people who provided a response that was coded into this category (with examples of the responses coded into this category) alongside the proportion of all Autistic people who provided a response that was coded into this category. Where there was a difference of 5% or more between Autistic CALD people and all Autistic people, the percentage difference is highlighted with bold and underlined text in the tables.

It is important to consider the small sample size ($n < 20$) for this priority group when interpreting the results in the following sections.

3.5.2.1.1 Problems experienced by Autistic people in relation to mental health services, as reported by Autistic people who are culturally and linguistically diverse

A total of 19 Autistic CALD people opted to answer this open-ended question in relation to mental health services. Table 51 ranks the problems that Autistic CALD people most frequently reported Autistic people experiencing in relation to mental health services (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 51: Most frequently reported problems experienced by Autistic people in relation to mental health services, as reported by Autistic culturally and linguistically diverse people

Rank	Problems experienced by Autistic people in relation to mental health services	% who stated this answer		
		Autistic culturally and linguistically diverse people <i>n</i> = 19	Entire Autistic sample <i>n</i> = 250	% difference
1	Prohibitive cost (e.g., very expensive; services able to charge too much)	23%	28%	<u>-5%</u>
2=	Insufficient availability/access of relevant, skilled mental health worker (e.g., lack of providers who can do assessments; challenges finding neurodivergent therapist)	21%	18%	3%
2=	Lack of knowledge or understanding of autism/neurodiversity, its presentation, and its impact across the lifespan (e.g., lack of knowledge about autism in females; lack of understanding of lived experience)	21%	28%	<u>-7%</u>
2=	Long or closed waitlists (e.g. long waiting time to access diagnostic services, psychologists, and psychiatrists; waiting lists exacerbate issues)	21%	19%	2%
5	Strategies not tailored for the individual client or neurodivergent people (e.g., not tailored for individual needs or preferred goals; neurotypical strategies do not always work for Autistic people)	16%	10%	<u>6%</u>

Rank	Problems experienced by Autistic people in relation to mental health services	% who stated this answer		
		Autistic culturally and linguistically diverse people <i>n</i> = 19	Entire Autistic sample <i>n</i> = 250	% difference
6=	Insufficient availability/access of appropriate services (e.g., lack of services specialising in autism; long distance to travel)	11%	17%	<u>-6%</u>
6=	Challenges accessing services due to lack of support, knowledge, or accommodations (e.g., challenges navigating the services; challenges booking appointments by telephone)	11%	6%	<u>5%</u>
6=	Challenges in forming therapeutic relationship (e.g., high turnover of staff impacting relationship building; limited time with therapist; practitioner poorly matched with client; not making client feel safe)	11%	4%	<u>7%</u>
6=	Lack of neurodiversity-affirming practice (e.g., encouraged to function in neurotypical way; trained to mask)	11%	6%	<u>5%</u>
6=	Sensory impact of mental health service environments (e.g., busy waiting room; sensory overload in waiting room; lack of appropriate spaces for Autistic people)	11%	3%	<u>8%</u>
6=	Mental health services not providing autism diagnosis or recognising autism characteristics (e.g., challenges obtaining referral for diagnosis; lack of identification of autism characteristics)	11%	6%	<u>5%</u>

3.5.2.1.2 Factors causing the problems experienced by Autistic people in relation to mental health services, as reported by Autistic people who are culturally and linguistically diverse

A total of 13 Autistic CALD people opted to answer this open-ended question on mental health services. Table 52 ranks the most commonly reported factors that respondents felt were causing the problems that Autistic people experience in relation to mental health services reported above (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group. As this is a small sample, caution should be aired when interpreting the results.

Table 52: Most frequently reported causes of the problems experienced by Autistic people in relation to mental health services, as reported by Autistic culturally and linguistically diverse people

Rank	Causes of the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic culturally and linguistically diverse people <i>n</i> = 13	Entire Autistic sample <i>n</i> = 213	% difference
1	Lack of, or poor quality of, training for mental health professionals (e.g., poor training; lack of training in diagnosing and treating autism appropriately)	46%	27%	<u>19%</u>
2=	Lack of knowledge or understanding of autism and neurodivergent conditions, its presentation, and its impact (e.g., lack of understanding the heterogeneous presentation of autism; lack of understanding of stresses associated with autism)	23%	28%	<u>-5%</u>
2=	Insufficient number of professionals with an interest/expertise in autism (e.g., lack of qualified people specialising in autism; lack of specialists in rural areas)	23%	12%	<u>11%</u>
4=	Insufficient funding (generally) (e.g., lack of funding; funding shortfall)	15%	15%	0%
4=	Impact of decisions made by the government (e.g., government policies; government cuts; poor management of mental health services)	15%	10%	<u>5%</u>

Rank	Causes of the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic culturally and linguistically diverse people <i>n</i> = 13	Entire Autistic sample <i>n</i> = 213	% difference
4=	Professionals may make assumptions or have preconceived ideas of autism (e.g., Autistic people are not competent; autism is a “male diagnosis”)	15%	8%	<u>7%</u>
4=	Lack of research and Autistic-informed care in mental health services (e.g., evidence base is needed for women and girls; lack of co-designed services with Autistic people)	15%	8%	<u>7%</u>
8=	Strategies and practices considered insufficient, inappropriate, or poor quality (e.g., lack of awareness of how to modify practices; neuro-normative concepts of well-being applied to Autistic people)	8%	9%	-1%
8=	Approaches currently focus on medical model rather than more inclusive approaches (e.g., medical model is a problem; interaction with society is the problem, not autism)	8%	6%	2%
8=	The system is challenging and is not designed to support the access/use of Autistic people (e.g., inflexible; access needs are not enquired about)	8%	6%	2%
8=	Challenges with NDIS access, funding, and misuse of funds by professionals (e.g., NDIS will not support mental health; NDIS planner not understanding the interaction between autism and mental health)	8%	6%	2%

3.5.2.1.3 Factors that could prevent or reduce the problems experienced by Autistic culturally and linguistically diverse people in relation to mental health services

A total of 15 Autistic CALD people opted to answer this open-ended question on mental health services. Table 53 ranks the most commonly reported factors that Autistic CALD people reported could prevent or reduce the problems that Autistic people experience in relation to accessing mental health services reported above (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 53: Most frequently reported factors that could prevent or reduce the problems experienced by Autistic people in relation to mental health services, as reported by Autistic culturally and linguistically diverse people

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic culturally and linguistically diverse people <i>n</i> = 15	Entire Autistic sample <i>n</i> = 199	% difference
1	Increase funding and/or affordability of mental health services across the lifespan (e.g., government funded functional capacity assessment; price caps and/or rebates)	33%	19%	<u>14%</u>
2	Increase (access to) training for people working as mental health professionals to enhance their understanding of autism (and other neurodivergence), including training from Autistic people with lived experience (e.g., mandatory, regular training; Autistic informed/delivered training)	27%	46%	<u>-19%</u>
3	Education to support general public's understanding of autism (e.g., address stigma; publicity drives to debunk myths and attitudes)	20%	7%	<u>13%</u>
4=	More mental health professionals, including those specialising in autism, and those who are Autistic/neurodivergent themselves (e.g., more doctors; more psychologists; create new roles and professions to support Autistic people; incentives for experts; alternative qualification pathways)	13%	19%	<u>- 6%</u>
4=	Implement Medicare-specific improvements for increasing affordability of mental health care (e.g., allow provisional psychologists to work under Medicare; Medicare funding for mental health)	13%	9%	4%

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic culturally and linguistically diverse people <i>n</i> = 15	Entire Autistic sample <i>n</i> = 199	% difference
4=	Enhance the quality of university education and number of places available (e.g., do not phase out psychology general registration pathway; provide education on neurodiversity-affirming practice; include information on co-occurring intellectual disability and other co-occurring conditions)	13%	9%	4%
4=	Facilitate changes to practice to focus on strengths, neurodiversity-affirming care, and skills relevant to supporting Autistic people (e.g., use social model rather than medical model; neurodiversity-affirming practice)	13%	10%	3%
8=	Improve access to, and quality of, services (e.g., reduce the red tape; consideration of access for regional and rural areas; services for people with complex needs)	7%	9%	-2%
8=	More co-produced research that provides evidence-based practices for neurodivergent people (e.g., include Autistic and neurodiverse people in research design; research needed into neuro-affirmative practice)	7%	7%	0%
8=	More consideration of the role of the family/parents and how they can be better supported (e.g., greater support for families; asking for and respecting family input; providing family with information)	7%	2%	<u>5%</u>
8=	Make access and use of services easier and more autism-friendly (e.g., alternative methods to book appointments, increased flexibility of appointments; environment)	7%	10%	-3%

3.5.2.1.4 Factors that are working well, or have worked well, for Autistic culturally and linguistically diverse people in relation to mental health services

Overall, 10 Autistic CALD people replied to this open-ended question. Table 54 ranks the eight most commonly reported factors that Autistic CALD people reported to be working well, or that have worked well, for Autistic people in relation to mental health (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

It is important to consider the small sample size for this question in particular, as it is at the very minimum number considered reportable within this document.

Table 54: Most frequently reported factors that are working well, or have worked well, for Autistic people in relation to mental health services, as reported by Autistic culturally and linguistically diverse people

Rank	What is working well, or has worked well, in relation to Autistic people's experiences with mental health services	% who stated this answer		
		Autistic culturally and linguistically diverse people <i>n</i> = 10	Entire Autistic sample <i>n</i> = 155	% difference
1=	Nothing/not a lot	20%	25%	<u>-5%</u>
1=	Accommodations to support Autistic people (e.g., informing clients of the steps; providing processing time; flexible; writing summaries of key ideas; more frequent shorter sessions; autism friendly sensory environments; clear information)	20%	7%	<u>13%</u>
1=	Support from family, friends, and Autistic/neurodivergent community (e.g., parent advocacy; ability to bring trusted person to appointments; social groups to meet other Autistic people)	20%	8%	<u>12%</u>
4=	When you find the right mental health professional for you, who is often knowledgeable/experienced about autism and its associated needs (e.g., understands autism and neurodiversity; experience working with Autistic people)	10%	18%	<u>-8%</u>
4=	When NDIS funding has been provided to support needs (e.g., NDIS can reduce mental health burden when all needs are covered; supportive NDIS plan manager)	10%	13%	-3%

Rank	What is working well, or has worked well, in relation to Autistic people’s experiences with mental health services	% who stated this answer		
		Autistic culturally and linguistically diverse people <i>n</i> = 10	Entire Autistic sample <i>n</i> = 155	% difference
4=	Affordable health care when it is accessible (e.g., cheap or free services with health care card; bulk billed; professions registered within “better access to mental health”; twenty extra sessions during COVID)	10%	7%	3%
4=	When a professional has lived experience (e.g., are Autistic/neurodivergent, or have Autistic family members)	10%	10%	0%
4=	The recent shift towards neurodiversity-affirming and strengths-based practice, rather than relying on medical model (e.g., focus on the strengths of a person rather than the challenges)	10%	9%	1%

3.5.2.2 Autism Connect dataset: Contacts relating to mental health

A total of 12 contacts to Autism Connect referred to mental health issues, specifically related to Autistic CALD people. This is a small number of contacts so the data need to be interpreted with caution. Table 55 ranks the most frequent mental health-related issues that people contacted the Autism Connect helpline to discuss. The data are ranked from most frequently reported to least frequently reported issues. Where there was a difference of 5% or more between the contacts related to Autistic CALD people and all Autistic people, the percentage difference is highlighted with bold and underlined text in the tables.

It is important to consider the small sample size ($n < 20$) for this priority group when interpreting the results.

Table 55: Most frequent mental health-related issues raised in contacts to Autism Connect by, or related to, Autistic culturally and linguistically diverse people

Topic (contacts)	Mental health issue raised	% contacts for mental health-related issues		
		Autistic culturally and linguistically diverse people <i>n</i> = 12	All contacts <i>n</i> = 1,514	% difference between groups
Seeking therapist (<i>n</i> = 10)	Psychologist	58.3%	55.2%	3.1%
	Psychiatrist	16.7%	12.4%	4.3%
	Support worker for mental health related reasons	8.3%	0.3%	<u>8%</u>
Advice (<i>n</i> =2)	Mental health advice	16.7%	10.3%	<u>6.4%</u>

3.5.2.3 “Making therapy better” questionnaire

A total of 22 respondents identified as Autistic and CALD in the questionnaire about ways of making mental health supports/therapy better for Autistic people. Here, Autistic people were asked how helpful specific activities, accommodations, or strategies would be if they were offered by a mental health practitioner or clinic. The five most helpful activities, accommodations, or strategies are listed in Table 56. Where there was a difference of 0.25 or more between Autistic CALD people and all Autistic people, the score difference is highlighted with bold and underlined text in the tables.

Table 56: Five most helpful activities, accommodations, or strategies that could be offered by a mental health practitioner or clinic, as rated by Autistic CALD people

Activity, accommodation, or strategy	Mean (SD) Autistic culturally and linguistically diverse people <i>n</i> = 22	Mean (SD) entire Autistic sample <i>n</i> = 130	Score difference for Autistic culturally and linguistically diverse people
If the psychologist had a high level of knowledge about autism	4.82 (.40)	4.78 (.53)	0.04
If the psychologist accepted your autism diagnosis or self-identification did not re-diagnose when you were seeking support for a different issue or goal	4.82 (.40)	4.44 (.94)	<u>0.38</u>
If the clinic provided the option to book online to make an appointment	4.77 (.53)	4.78 (.64)	-0.01
If the psychologist used questionnaires or measures in therapy designed by and/or with Autistic people	4.73 (.55)	4.48 (.86)	<u>0.25</u>
If the psychologist used a neurodiversity-affirming approach (e.g., embraces differences in brains and provides supports to affirm neurodivergent identity)	4.73 (.55)	4.71 (.60)	0.02

The five least helpful activities, accommodations, or strategies are listed in Table 57.

Table 57: Five least helpful activities, accommodations, or strategies that could be offered by a mental health practitioner or clinic, as rated by Autistic CALD people

Activity, accommodation, or strategy	Mean (SD) Autistic culturally and linguistically diverse people <i>n</i> = 22	Mean (SD) entire Autistic sample <i>n</i> = 130	Score difference for Autistic culturally and linguistically diverse people
If therapy is provided in groups with other Autistic people	2.36 (1.26)	2.32 (1.13)	0.04
If therapy is provided via telephone	2.41 (1.37)	2.14 (1.23)	<u>0.27</u>
If sessions were shorter (< 50 minutes)	2.41 (1.22)	2.10 (1.14)	<u>0.31</u>
If the psychologist changed their own body language, facial expressions or eye contact in response to your preferences	2.73 (1.42)	3.22 (1.28)	<u>-0.49</u>
If the psychologist involved a family member or partner in sessions	2.86 (1.32)	2.60 (1.30)	<u>0.26</u>

3.5.3 Summary of existing data for Autistic culturally and linguistically diverse people

3.5.3.1 Summary of differences noted in the data for Autistic culturally and linguistically diverse people as compared to the data for the entire Autistic sample

The focus in this section is on any items that differed between data provided by, or in relation to, Autistic CALD people and the data for the entire Autistic sample. A general summary of the issues with health and mental health services raised by, or in relation to, Autistic CALD people is provided in Section 3.5.3.2.

There were **49 items** in which the data for Autistic CALD people differed substantially compared to the entire sample of Autistic people; 17 related to physical health care experiences and 32 related to mental health care service experiences. These are summarised Figure 9, Figure 10 and Figure 11.

The definitions used and calculations of substantial differences are described in the method section. This large number of differences highlights that the experiences of Autistic CALD people accessing physical health care and mental health care services in Australia need further exploration through in-depth discussions or focus groups.

Considering the large number of substantial difference, it is more important that each item in the Figures below be considered so as to gain insight into the scale and breadth of the issues raised. The items where the data provided by, or in relation to, Autistic CALD people highlighted a substantial difference from the entire sample of Autistic people predominantly focused upon the health care professionals' approaches (including ableism or not using neurodiversity-affirming approaches), the provision of accommodations and adaptations, funding and the importance of Autistic (e.g. advocates, Autistic employees) or family input into sessions or services. There was also a number of items relating to the lack of mental health practitioners with knowledge of autism and the importance of autism training mental health practitioners to ensure they use autism-specific approaches to assessment or therapy.

Figure 9: Summary of substantial differences in existing datasets reporting on physical health service experiences for Autistic culturally and linguistically diverse people

In relation to physical health services, Autistic culturally and linguistically diverse people were more likely to...

- ▲ Report that nothing/not a lot is working well or has worked well (+22%; “1,000 insights” survey).
- ▲ Report professional’s therapeutic skills as a problem (+17%; “1,000 insights” survey).
- ▲ Report when health care services are affordable and there is access to funding (beyond NDIS) as working/having worked well (+14%; “1,000 insights” survey).
- ▲ Report neurotypical/majority needs being prioritised, ableism, and a lack of neurodiversity-affirming practice as causing problems (+10%; “1,000 insights” survey).
- ▲ Report that increasing the number of health care professionals and services available could reduce the problems (+10%; “1,000 insights” survey).
- ▲ Report government reform, support, and guidance could reduce the problems (+9%; “1,000 insights” survey).
- ▲ Report when Autistic individuals feel supported in using physical health services through the growing autism movement, Autistic advocates, collaboration with Autistic partners and awareness in the community, as working/having worked well (+8%; “1,000 insights” survey).
- ▲ Report a lack of individual supports and accommodations as causing the problems (+8%; “1,000 insights” survey).
- ▲ Report dismissing or excluding an Autistic person or their family as causing the problems (+7%; “1,000 insights” survey).
- ▲ Report physical health care providers dismissing or not believing the reports of Autistic people or their family members (including not believing a person is Autistic) as a problem (+7%; “1,000 insights” survey).
- ▲ Report increasing funding/resources and/or affordability of health services across the lifespan could reduce the problems (+6%; “1,000 insights” survey).
- ▲ Report that increasing communication options to improve access to health care and access to information about health care could reduce the problems (+6%; “1,000 insights” survey).
- ▲ Report health professionals’ reluctance to adapt practices or provide accommodations/supports for Autistic individuals as problem (+5%; “1,000 insights” survey).
- ▲ Report that employing, consulting, and collaborating with neurodivergent practitioners, support workers, advocates, and those in leadership/decision-making roles could reduce the problems (+5%; “1,000 insights” survey).

In relation to physical health services, Autistic culturally and linguistically diverse people were less likely to...

- ▼ Report the sensory elements of physical health services or settings (including waiting rooms and emergency departments) as a problem (-8%; “1,000 insights” survey).
 - ▼ Report finding the right physical health provider for you, who was often described as knowledgeable about autism, understanding, caring, patient, and non-judgemental, as working/having worked well (-11%; “1,000 insights” survey).
 - ▼ Report that education, training, and upskilling programs for health care professionals and administrative staff about autism, characteristics and health impacts could reduce the problems (-20%; “1,000 insights” survey)
-

Figure 10: Summary of substantial differences in existing datasets reporting on mental health service experiences for Autistic culturally and linguistically diverse people

In relation to mental health services, Autistic culturally and linguistically diverse people were more likely to...

- ▲ Report a lack of, or poor quality of, training for mental health professionals as a cause of the problems (+19%; “1,000 insights” survey).
- ▲ Report that increasing funding and/or affordability of mental health services across the lifespan could reduce the problems (+14%; “1,000 insights” survey).
- ▲ Think that shorter sessions (<50 minutes) would be a helpful activity, accommodation or strategy (+0.31; “Making therapy better” questionnaire).
- ▲ Report that accommodations to support Autistic people are working/have worked well (+13%; “1,000 insights” survey).
- ▲ Report that education to support general public’s understanding of autism could reduce the problems (+13%; “1,000 insights” survey).
- ▲ Think that providing therapy via telephone as a helpful activity, accommodation or strategy (+0.27; “Making therapy better” questionnaire).
- ▲ Report that support from family, friends, and Autistic/neurodivergent community is working/has worked well (+12%; “1,000 insights” survey).
- ▲ Think that a psychologist involving a family member or partner in sessions is a helpful activity, accommodation or strategy (+0.26; “Making therapy better” questionnaire).
- ▲ Report an insufficient number of professionals with an interest/expertise in autism, as a cause of the problems (+11%; “1,000 insights” survey).
- ▲ Rate psychologists accepting their autism diagnosis or self-identification as a helpful activity, accommodation or strategy (+0.38; “Making therapy better” questionnaire).
- ▲ Report the sensory impact of mental health environments as a problem (+8%; “1,000 insights” survey).
- ▲ Make contact with Autism Connect, or have contact made about them, for assistance finding a support worker (+8%).
- ▲ Report professionals making assumptions or having preconceived ideas of autism as a cause of the problems (+7%; “1,000 insights” survey).
- ▲ Report a lack of research and Autistic-informed care in mental health services as a cause of the problems (+7%; “1,000 insights” survey).
- ▲ Report challenges in forming a therapeutic relationship as a problem (+7%; “1,000 insights” survey).
- ▲ Make contact with Autism Connect, or have contact made about them, for mental health advice (+6.4%).
- ▲ Report strategies not being tailored for the individual client or neurodivergent people as a problem (+6%; “1,000 insights” survey).
- ▲ Report decisions made by the government as a cause of the problems (+5%; “1,000 insights” survey).
- ▲ Rate psychologists using questionnaires or measures in therapy designed by and/or with Autistic people as a helpful activity, accommodation, or strategy (+0.25; “Making therapy better” questionnaire).

- ▲ Report that increasing consideration of the role of the family/parents, and how they can be better supported, could reduce the problems (+5%; “1,000 insights” survey).
- ▲ Report challenges accessing services due to a lack of support, knowledge, or accommodations as a problem (+5%; “1,000 insights” survey).
- ▲ Report a lack of neurodiversity affirming practice as a problem (+5%; “1,000 insights” survey).
- ▲ Report mental health services not providing an autism diagnosis, or not recognising autism characteristics, as a problem (+5%; “1,000 insights” survey).

Figure 11: Summary of substantial differences in existing datasets reporting on mental health service experiences for Autistic culturally and linguistically diverse people

In relation to mental health services, Autistic culturally and linguistically diverse people were less likely to...

- ▼ Report that nothing/not a lot is working well or has worked well (-5%; “1,000 insights” survey).
 - ▼ Report prohibitive cost as a problem (-5%; “1,000 insights” survey).
 - ▼ Consider professionals’ lack of knowledge or understanding about autism as the cause of the problems experienced within the mental health service (-5%; “1,000 insights” survey).
 - ▼ Report increasing the number of mental health professionals, including those specialising in autism, and those who are Autistic/neurodivergent themselves, could reduce the problems (-6%; “1,000 insights” survey).
 - ▼ Report insufficient availability/access of appropriate services as a problem (-6%; “1,000 insights” survey).
 - ▼ Report lack of knowledge or understanding of autism/neurodiversity, its presentation, and its impact across the lifespan as a problem within the mental health service (-7%; “1,000 insights” survey).
 - ▼ Report that finding the right mental health professional for you, who is often knowledgeable/experienced about autism and its associated needs is working/has worked well (-8%; “1,000 insights” survey).
 - ▼ Report that increasing (access to) training for people working as mental health professionals to enhance their understanding of autism (and other neurodivergence), including training from Autistic people with lived experience, could reduce the problems (-19%; “1,000 insights” survey).
 - ▼ Rate when psychologists changed their own body language, facial expressions or eye contact in response to your preferences as a less helpful activity, accommodation or strategy (-0.49; “Making therapy better” questionnaire).
-

3.5.3.2 Summary of issues or experiences with physical and/or mental health services for Autistic culturally and linguistically diverse people as reported in the four datasets

The data reflect information gathered in multiple ways: (a) open text answers to a survey, (b) rating level of agreement on a rating scale, and (c) contact with Autism Connect. Despite these differences in how the data were obtained, commonalities were identified across the physical and mental health service domains. These commonalities are discussed below. It is important, however, that we also take the time to consider the responses unique to each individual domain or dataset as these provide important insights in the challenges experienced within a specific service.

Factors common across physical and mental health services: Commonalities in the problems identified by Autistic CALD people across the physical and mental health service domains include:

- a. professionals **dismissing or not believing** the experiences of Autistic people
- b. professionals holding a **limited knowledge of autism** and its presentation
- c. the **reluctance of professionals to adapt practices/strategies** or accommodations to support Autistic people
- d. **challenges accessing** appropriate services
- e. large or prohibitive **costs** associated with the service
- f. challenges associated with the **sensory elements** of health care settings and
- g. concerns about the **therapeutic skills of professionals**.

These problems may also be reflected in the Autism Connect helpline data, where more contacts were made by or for Autistic CALD people for mental health therapist recommendations and mental health advice than by or for Autistic people not identified as CALD.

The first five themes (a to e) reported above were echoed in both what Autistic CALD people perceive to be the causes of these problems, and strategies that could be used to reduce them. Specifically, many people identified that **professionals made assumptions about or dismissed the lived experience** of Autistic people. This could be linked with the commonly reported **lack of knowledge held by professionals** regarding autism, neurodiversity, and the varied presentations across people and the lifespan, which was attributed as a cause of challenges experienced within the health system. To support an increase in health professionals' knowledge, Autistic people advocated **increasing affordable or funded access to autism education**, training, and upskilling programs, therefore increasing the number of professionals knowledgeable about autism and its presentations. Ideally this education would be developed and delivered in collaboration with neurodivergent practitioners and/or people with lived experience. This increased knowledge, in turn, could support professionals to **consider the practices (including neurodiversity-affirming approaches), strategies, and accommodations available**, and to tailor these to support Autistic people's access to and use of health care systems. These changes could also assist in improving the systems to **access these health care services** by, for example, increasing communication options (e.g., online booking, telehealth) and considering the sensory environment, therefore making the services more autism friendly. Finally, Autistic CALD people advocated for ways to **financially support access** to these services, whether this be by reducing the cost of the services or increasing access to funding across the lifespan (e.g., Medicare, NDIS).

A further factor that was raised by, or in relation to, Autistic CALD people was the need for **additional health care providers, including those with expertise in autism and/or lived experience**. Having these additional, knowledgeable practitioners could improve access to these important mental and physical health services.

3.5.4 Summary

A large number ($n = 49$) of substantial differences were observed between the data reporting on Autistic CALD people, or those who were contacting, and the entire sample of Autistic people within the datasets. This highlights the importance of working with Autistic people within this priority group to better understand their experiences and ways that assistance can be provided to better support access to, and use of, health care services within Australia. This need is further emphasised given that only a relatively small number of respondents from these large datasets were identified as CALD. By conducting further consultations with this group, we may be better placed to also understand the reason for the differences in the perspectives and experiences of Autistic CALD people compared to the entire sample of Autistic people in this study and the impact they may be having on the physical health and mental health outcomes of Autistic CALD people in Australia.

It is important to consider that not all pre-existing datasets enquired as to the cultural or linguistic background of the Autistic people who provided information (or from whom information was provided). Future work should ensure that these data are collected, so as to allow for a better understanding of this priority group to be obtained.

3.6 Autistic First Nations people

3.6.1 Physical health services

3.6.1.1 The “1,000 insights” community views survey physical health services

Only five Autistic First Nations people answered the questions on physical health services on this survey. This is not a sufficient sample size to report upon, and highlights a clear need to work with this community to extend knowledge on this issue.

3.6.1.2 Autism Connect dataset: Contacts relating to physical health

A total of three contacts to Autism Connect referred to physical health-related issues, specifically in relation to Autistic First Nations people. This is not a sufficient number of contacts from which to draw conclusions, so the data are not reported here. This highlights a clear need to work with this community to extend knowledge on this issue.

3.6.1.3 “Barriers to care” questionnaire

Only six people who identified as Autistic First Nations people responded to this questionnaire that asked them to rank predetermined statements relating to barriers to accessing acute physical health care. This is not a sufficient sample size to report upon, highlighting a clear need to work with this community to extend knowledge on this issue.

3.6.2 Mental health services

3.6.2.1 The “1,000 insights” community views survey mental health services

A total of five Autistic First Nations people answered at least one of the questions on mental health services. This is not a sufficient sample on which to report data, highlighting an urgent need for collaborative consultations in this area.

3.6.2.2 Autism Connect dataset: Contacts relating to mental health

A total of 12 contacts to Autism Connect were in relation to Autistic First Nations people. This is a small sample size so caution must be used when reading and interpreting the data. The most frequent mental health issues that the contact related to are reported within this section. Table 58 ranks the most frequent mental health-related issues that people contacted the Autism Connect helpline to discuss. The data are ranked from most frequently reported to least frequently reported issues. Where there was a difference of 5% or more between the contacts related to Autistic First people and all Autistic people, the percentage difference is highlighted with bold and underlined text in the tables.

It is important to consider the small sample size ($n < 20$) for this priority group when interpreting the results.

Table 58: Most frequent mental health-related issues raised in contacts to Autism Connect by, or related to, Autistic First Nations people

Topic (contacts)	Mental health issue raised	% contacts for mental health-related issues		
		For Autistic First Nations people <i>n</i> = 12	All contacts <i>n</i> = 1,514	% difference between groups
Seeking therapist (<i>n</i> = 9)	Psychologist	41.8%	55.2%	<u>-13.4%</u>
	General therapists (mental health reasons)	8.3%	3.7%	4.6%
	Animal therapy for mental health	8.3%	0.3%	<u>8.0%</u>
	Other or unspecified mental health support	8.3%	5.6%	2.7%
	Psychiatrist	8.3%	12.4%	-4.1%
Advice (<i>n</i> = 3)	Mental health advice	16.7%	10.3%	<u>6.4%</u>
	Work or employment, relating to mental health	8.3%	2.0%	<u>6.3%</u>

3.6.2.3 “Making therapy better” questionnaire

Only two respondents identified as Autistic First Nations people, which is not a sufficient sample size on which to report. This highlights a clear need to work with this community to extend knowledge on this issue.

3.6.3 Summary

Across the datasets, there was only data reported by or in relation to 33 Autistic First Nations people ($n = 14$ and 19 , respectively). Given the large scale of these datasets, this highlights the extreme under-representation of Autistic First Nations people. As such, we are unable to draw any conclusions about the experiences of this priority group from existing datasets. Instead, this illustrates a clear need for collaborative, community-led consultation to understand the barriers and facilitators experiences by Autistic First Nations people when accessing and using physical and mental health services in Australia.

3.7 Autistic people with high or complex disability needs

3.7.1 Physical health services

3.7.1.1 The “1,000 insights” community views survey physical health services

A total of 26 Autistic people with high or complex disability needs answered at least one of the four open-ended questions on physical health services. These questions were:

- What are three problems that Autistic people experience when accessing, or trying to access, physical health services?
- What do you think is causing these problems?
- What do you think could prevent or reduce these problems?
- What is working well, or has worked well, for Autistic people in relation to physical health care services?

The most frequently reported responses to each of the questions are reported within this section. The tables include the proportion of Autistic people with high or complex disability needs who provided a response that was coded into this category (with examples of the responses coded into this category) alongside the proportion of all Autistic people who provided a response that was coded into this category. Where there was a difference of 5% or more between the Autistic people with high or complex disability needs and all Autistic people, the percentage difference is highlighted with bold and underlined text in the tables.

It is important to consider the relatively small sample size ($n < 30$) for this priority group when interpreting the results in the following sections.

3.71.1.1 Problems experienced by Autistic people in relation to physical health services, as reported by Autistic people with high or complex disability needs.

A total of 26 Autistic people with high or complex disability needs opted to answer this open-ended question in relation to physical health services. Table 59 ranks the problems that Autistic people with high or complex disability needs most frequently reported Autistic people experiencing in relation to physical health services (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 59: Most frequently reported problems experienced by Autistic people in relation to physical health services, as reported by Autistic people with high or complex disability needs

Rank	Problems experienced by Autistic people in relation to physical health services	% who stated this answer		
		Autistic people with high or complex disability needs <i>n</i> = 26	Entire Autistic sample <i>n</i> = 253	% difference
1	Physical health care providers dismissing or not believing the reports of Autistic people or their family members (including not believing a person is Autistic) (e.g., dismissing symptoms or requests)	31%	16%	<u>15%</u>
2	Concerns about professional’s therapeutic skills (e.g., lack of patience, empathy, care or understanding; mistreatment)	27%	16%	<u>11%</u>
3=	The sensory elements of physical health services or settings (including waiting rooms and emergency departments) are not supportive for Autistic people, sometimes leading to sensory overwhelm (e.g., crowded, bright and noisy waiting rooms)	12%	19%	<u>-7%</u>
3=	Differences or difficulties with communication, including Autistic people experiencing challenges with describing their experiences, having to frequently repeat information to providers, and physical health providers not presenting information in a way that is accessible to Autistic people (e.g., difficulties or fears associated with articulating needs or feelings)	12%	17%	<u>-5%</u>
3=	Adjustments or accommodations not offered, or system not taking into account needs or preferences of Autistic people (e.g., appointments or therapies not autism-friendly; options for appointments [telehealth or in person]; and the process of arranging appointments or communicating with staff outside of appointments)	12%	15%	-3%

Rank	Problems experienced by Autistic people in relation to physical health services	% who stated this answer		
		Autistic people with high or complex disability needs <i>n</i> = 26	Entire Autistic sample <i>n</i> = 253	% difference
6=	Poor clinical decisions (e.g., misdiagnosing; reactive not preventative focus)	15%	9%	6%
6=	Health professionals' reluctance to adapt practices or provide accommodations/supports for Autistic individuals (e.g., inflexibility, one-size-fits-all, lack of neurodiversity-affirming care)	15%	17%	-2%
6=	Lack of health professionals and services, and disparity based on location (i.e., regional and rural) (e.g., limited number of allied health and medical professionals; no services for particular age group/gender)	15%	8%	7%
6=	Challenges accessing sufficient funding to support physical health (e.g., Medicare support; bulk-billing services; NDIS funding)	15%	7%	8%
10=	Lack of knowledge on atypical presentations (including pain and masking) and treatment of health problems in Autistic people (e.g., lack of understanding about the diversity of sensory responses, presentation of characteristics in Autistic women and girls, and mental health needs of Autistic people)	12%	15%	-3%
10=	Long waiting lists to access physical health services (e.g., long waiting time to access diagnostic, generalised and specialised services)	12%	13%	-1%
10=	Difficulties with the process to access and physically attend health services (e.g., organising and understanding forms, service availability/options, paperwork and appointments; transport)	12%	12%	0%
10=	Services are too expensive to access	12%	13%	-1%

3.7.1.1.2 Factors causing the problems experienced by Autistic people in relation to physical health services, as reported by Autistic people with high or complex disability needs

A total of 21 Autistic people with high or complex disability needs opted to answer this open-ended question on physical health services. Table 60 ranks the most commonly reported factors that respondents felt were causing the problems that Autistic people experience in relation to physical health services reported above.

Table 60: Most frequently reported causes of the problems experienced by Autistic people in relation to physical health services, as reported by Autistic people with high or complex disability needs

Rank	Causes of the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic people with high or complex disability needs <i>n</i> = 21	Entire Autistic sample <i>n</i> = 216	% difference
1	Staff in health care settings (including administrative settings) have a lack of knowledge or understanding of autism/ neurodiversity, diversity of presentations, and how autism/neurodivergence may impact physical health needs or symptoms, such as pain (e.g., lack of understanding individual needs; lack of understanding of autism; outdated knowledge)	38%	32%	<u>6%</u>
2=	Dismissing or excluding an Autistic person or their family (e.g., lack of questioning; ignoring symptoms and health concerns)	19%	8%	<u>11%</u>
2=	Neurotypical/majority needs prioritised, ableism, and lack of neurodiversity-affirming practice (e.g., services are not designed to be inclusive of Autistic people; there is an emphasis on the needs of the practitioner and non-Autistic clients)	19%	13%	<u>6%</u>
4=	Health professionals' reluctance to adapt practices or provide accommodations/supports for Autistic individuals (e.g., inflexibility, one-size-fits-all, lack of neurodiversity-affirming care)	14%	7%	<u>7%</u>
4=	Lack of funding/resources and/or difficulty accessing these supports (including the high costs of health care)	14%	18%	-4%

Rank	Causes of the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic people with high or complex disability needs <i>n</i> = 21	Entire Autistic sample <i>n</i> = 216	% difference
4=	Lack of communication accommodations (e.g., booking and therapy options; language used; and non-verbal alternatives)	14%	7%	<u>7%</u>
7=	Health professionals' reluctance to adapt practices or provide accommodations/supports for Autistic individuals or to see Autistic clients (e.g., inflexibility; refusal to see Autistic clients)	10%	7%	3%
7=	Lack of funding for autism education, training, and upskilling of physical health care professionals (e.g., lack of training within undergraduate and postgraduate level; insufficient on-going professional development and Autistic-led training)	10%	26%	<u>-16%</u>
7=	Lack of individual supports and accommodations (e.g., lack of knowledge of accommodations)	10%	7%	3%
7=	Neurotypical/majority needs prioritised, ableism, and lack of neurodiversity-affirming practice	10%	13%	-3%
7=	Lack of government support and guidance (e.g., a lack of autism-specific research; lack of guidelines/policy; increased red tape and bureaucracy)	10%	10%	0%
7=	Systems are complex to access and there is a lack of support, resources and/or education to access physical health services (e.g., absence of advocates; difficulty with)	10%	5%	<u>5%</u>
7=	Communication, processing, and social interaction differences and/or difficulties (e.g., processing issues; having to repeat information)	10%	7%	3%

3.7.1.1.3 Factors that could prevent or reduce the problems experienced by Autistic people in relation to physical health services, as reported by Autistic people with high or complex disability needs.

A total of 18 Autistic people with high or complex disability needs opted to answer this open-ended question on physical health services. Table 61 ranks the most commonly reported factors that Autistic people with high or complex disability needs reported could prevent or reduce the problems that Autistic people experience in relation to accessing physical health services reported above.

It is important to consider the small sample size for this priority group when interpreting the results.

Table 61: Most frequently reported factors that could prevent or reduce the problems experienced by Autistic people in relation to physical health services, as reported by Autistic people with high or complex disability needs

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic people with high or complex disability needs <i>n</i> = 18	Entire Autistic sample <i>n</i> = 210	% difference
1	Increase (access to) education, training, and upskilling programs for health care professionals and administrative staff about autism, characteristics, and health impacts (e.g., mandatory onboarding; Autistic informed/delivered training; and university level training)	33%	51%	<u>-18%</u>
2	Government reform, support, and guidance (e.g., investment in research and services; guidelines, policy and regulations)	28%	14%	<u>14%</u>
3	Increase communication options to improve access to health care and access to information about health care (e.g., web-based booking systems; text-based communication; opting in or out of telehealth [i.e., not assuming it is preferred or unpreferred])	22%	17%	<u>5%</u>
4=	Enhance the therapeutic skills and awareness of health care professionals to support their work with Autistic clients (e.g., acceptance; showing empathy and patience)	17%	12%	<u>5%</u>

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic people with high or complex disability needs <i>n</i> = 18	Entire Autistic sample <i>n</i> = 210	% difference
4=	Listen, validate and take concerns of Autistic individuals and their families/carers seriously (e.g., asking questions, working in partnership with clients)	17%	9%	<u>8%</u>
6=	Increase access and use of physical health care services for Autistic people and their families through the provision of accommodations, flexible access options, and supports (e.g., increased flexibility; and increased access to supports)	11%	14%	-3%
6=	Increase continuity of care, coordination of care and communication between service providers and care teams (e.g., increasing access to funding; increasing bulk-billing services; reviewing funding systems such as NDIS)	11%	5%	<u>6%</u>
6=	Change the diagnostic criteria for autism and diagnostic processes (e.g., including changing the level system, definition of autism spectrum disorder)	11%	4%	<u>7%</u>
6=	Increase funding/resources and/or affordability of health services across the lifespan (e.g., increasing access to funding; increasing bulk-billing services; reviewing funding systems such as NDIS)	11%	17%	<u>-6%</u>
10=	Increase community awareness about autism (e.g., public education programs, media campaigns, wider dissemination of knowledge, reducing stigma/ stereotypes)	6%	5%	1%
10=	Reduce the cost of health care services (including medications, diagnosis, and health care programs)	6%	6%	0%

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to physical health services	% who stated this answer		
		Autistic people with high or complex disability needs <i>n</i> = 18	Entire Autistic sample <i>n</i> = 210	% difference
10=	Create sensory-friendly physical health services or settings, including training to inform health care professionals of how overwhelming these environments can be for Autistic people and the impact this may have on their appointment (e.g., create sensory friendly waiting rooms and emergency departments)	6%	11%	<u>-5%</u>
10=	Increase the number of health care professionals and health services available (e.g., through incentives to increase rural/regional service; broadening scope of practice for health professionals)	6%	13%	<u>-7%</u>

3.7.1.1.4 Factors that are working well, or have worked well, for Autistic people in relation to physical health services, as reported by Autistic people with high or complex disability needs

Overall, 18 Autistic people with high or complex disability needs replied to this open-ended question. Table 62 ranks the six most commonly reported factors that Autistic people with high or complex disability needs reported to be working well, or that have worked well, for Autistic people in relation to physical health services.

It is important to consider the small sample size for this priority group when interpreting the results.

Table 62: Most frequently reported factors that are working well, or have worked well, for Autistic people in relation to physical health services, as reported by Autistic people with high or complex disability needs

Rank	What is working well, or has worked well, in relation to Autistic people’s experiences with physical health services	% who stated this answer		
		Autistic people with high or complex disability needs <i>n</i> = 18	Entire Autistic sample <i>n</i> = 161	% difference
1	When you find the right physical health provider for you, who was often described as knowledgeable about autism, understanding, caring, patient, and non- judgemental (e.g., compassionate; gentle; empathetic)	33%	21%	<u>12%</u>
2	When there are increased communication options to improve access to, and information about, health care (e.g., web-based booking systems; option of telehealth; non-verbal communication options)	28%	12%	<u>16%</u>
3=	Nothing/not a lot	17%	28%	<u>-11%</u>
3=	When providers ask questions and listen to Autistic people and/or their family members, and include Autistic individuals and their families in health care decisions (e.g., open communication; respectful practice; seeking consent, preferences, and opinions)	17%	8%	<u>9%</u>
3=	When health spaces are comfortable and sensory-friendly (e.g., calm waiting rooms; alternative meeting spaces; virtual reality; dim lights)	17%	6%	<u>11%</u>

Rank	What is working well, or has worked well, in relation to Autistic people's experiences with physical health services	% who stated this answer		
		Autistic people with high or complex disability needs <i>n</i> = 18	Entire Autistic sample <i>n</i> = 161	% difference
7=	When health care services are affordable and there is access to funding (beyond NDIS) (e.g., Medicare rebates; bulkbilling; and Health Care cards)	11%	6%	5%
7=	When supports are provided to prepare Autistic individuals for accessing health care services or initiatives/ supports that help access to health services (e.g., preparation resources for Autistic individuals; access to support workers; educated carers/families; supports for families)	11%	7%	4%
9=	Increased delivery of autism training and education to health professionals	6%	2%	4%
9=	Health care providers having an awareness and knowledge of autism, the characteristics of autism (including sensory needs) and different presentations (including the presentation of autism in women or girls)	6%	6%	0%
9=	When health care providers proactively ask about and provide alternative/flexible access, accommodations and/or support for Autistic individuals (e.g., longer appointments; more flexibility with appointments; support people attending; home visits)	6%	9%	-3%
9=	When there is an increased access to health professionals and services (e.g., Autistic led services; services that have expertise in autism)	6%	7%	-1%
9=	When there are improved health services and practices (including increased research)	6%	1%	5%

3.7.1.2 Autism Connect dataset: Contacts relating to physical health

A total of 28 contacts to Autism Connect referred to physical health-related issues, specifically in relation to Autistic people with high or complex disability needs. The most frequent physical health issues that the contact related to are reported within this section. Table 63 ranks the most frequent physical health-related issues that people contacted the Autism Connect helpline to discuss. The data are ranked from most frequently reported to least frequently reported issues. Where there was a difference of 5% or more between the contacts related to Autistic people with high or complex disability needs and all Autistic people, the percentage difference is highlighted with bold and underlined text in the tables.

Table 63: Most frequent physical health-related issues raised in contacts to Autism Connect by, or related to, Autistic people with high or complex disability needs

Topic (contacts)	Physical health issue raised	% contacts for physical health-related issues		
		For people with high or complex disability needs <i>n</i> = 28	All contacts <i>n</i> = 292	% difference between groups
Finding a health care provider (<i>n</i> = 23)	Other physical health care professionals	39.3%	21.2%	<u>18.1%</u>
	GP	28.6%	23.3%	<u>5.3%</u>
	Paediatrician	7.1%	14.7%	<u>-7.6%</u>
	Support worker (physical health reasons)	3.6%	1.0%	2.6%
	Nutrition or dietetics	3.6%	19.2%	<u>-15.6%</u>
Funding information (<i>n</i> = 1)	Non-NDIS funding (physical health reasons)	3.6%	1.0%	2.6%
Advice (<i>n</i> = 4)	Physical health advice	14.3%	14.0%	0.3%

3.7.1.3 “Barriers to care” questionnaire

A total of 34 people reporting on Autistic children with high or complex disability needs responded to the questionnaire that asked them to rank predetermined statements relating to barriers to accessing acute physical health care. This included 26 children with an intellectual disability, one child who was described as non-speaking, and 20 who were described as having high communication or behaviour needs (11 children had both an intellectual disability and high communication or behaviour needs; one child identified as having all three profiles). The five barriers on the “Barriers to care” questionnaire with the highest mean scores (i.e., happen most frequently) for Autistic children with high or complex disability needs are represented in Table 64. Where there was a difference of 0.25 or more between parent ratings for Autistic children with high or complex disability needs and all Autistic children, the score difference is highlighted with bold and underlined text in the tables.

Table 64: Five highest scoring barriers to acute physical health care on the “Barriers to care” questionnaire, as reported by parents of Autistic children with high or complex disability needs

“Barriers to care” questionnaire Question	Mean (SD) Autistic children with high or complex disability needs <i>n</i> = 34	Mean (SD) entire sample <i>N</i> = 107	Score difference for Autistic children with high or complex disability needs
Having to wait too long in the waiting room	3.79 (1.43)	3.96 (1.30)	-0.17
Getting hold of the doctor	3.74 (1.36)	3.86 (1.32)	-0.12
Getting a thorough examination	3.74 (1.27)	3.62 (1.33)	0.12
Worrying that doctors and nurses will not do what is right for your Autistic child	3.62 (1.37)	3.64 (1.34)	-0.02
Having to take care of household responsibilities	3.44 (1.50)	3.36 (1.36)	0.08

The five barriers on the “Barriers to care” questionnaire with the lowest mean scores (i.e., happen least frequently) for Autistic children with high or complex disability needs are represented in Table 65.

Table 65: Five lowest scoring barriers to acute physical health care on the “Barriers to care” questionnaire, as reported by parents of Autistic children with high or complex disability needs

“Barriers to care” questionnaire Question	Mean (SD) Autistic children with high or complex disability needs <i>n</i> = 34	Mean (SD) entire sample <i>N</i> = 107	Score difference for Autistic children with high or complex disability needs
Doctors or nurses not fluent in your language	1.06 (.24)	1.41 (.98)	<u>-0.35</u>
Doctors not believing in home or traditional remedies	1.41 (.86)	1.70 (1.26)	<u>-0.29</u>
Getting enough help with paperwork or forms	1.44 (1.02)	1.70 (1.19)	<u>-0.26</u>
Understanding doctors’ orders	1.62 (.92)	1.54 (.91)	0.08
Doctors or nurses who speak in a way that is too technical or medical	1.71 (1.06)	1.91 (1.07)	-0.2

3.7.2 Mental health services

3.7.2.1 The “1,000 insights” community views survey mental health services

A total of 58 Autistic people with high or complex disability needs answered at least one of the four open-ended questions on mental health services. These four questions were:

- What are three problems that Autistic people experience when using, or trying to access, mental health services?
- What do you think is causing these problems?
- What do you think could prevent or reduce these problems?
- What is working well, or has worked well, for Autistic people when using or trying to access mental health services?

High or complex disability needs is here defined as Autistic people who are living in out-of-home-care or living in supported accommodation, who have intellectual disability, who are full-time or part-time AAC users, and/or who are non-speaking. The most frequently reported responses to each of the questions are reported within this section. The tables include the proportion of Autistic people with high or complex disability needs who provided a response that was coded into this category (with examples of the responses coded into this category) alongside the proportion of all Autistic people who provided a response that was coded into this category. Where there was a difference of 5% or more between Autistic people with high or complex disability needs and all Autistic people, the percentage difference is highlighted with bold and underlined text in the tables.

3.7.2.1.1 Problems experienced by Autistic people in relation to mental health services, as reported by Autistic people with high or complex disability needs

A total of 27 Autistic people with high or complex disability needs opted to answer this open-ended question in relation to mental health services. Table 66 ranks the 11 problems that Autistic people with high or complex disability need most frequently reported Autistic people experiencing in relation to mental health services (based on the survey responses). The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 66: Most frequently reported problems experienced by Autistic people in relation to mental health services, as reported by Autistic people with high or complex disability needs

Rank	Problems experienced by Autistic people in relation to mental health services	% who stated this answer		
		Autistic people with high or complex disability needs <i>n</i> = 27	Entire Autistic sample <i>n</i> = 250	% difference
1=	Misdiagnosis of autism and/or co-occurring conditions (e.g., misdiagnosing autism as, for example, a personality disorder; diagnostic overshadowing)	26%	12%	<u>14%</u>
2	Insufficient availability/access of appropriate services (e.g., lack of services specialising in autism; long distance to travel)	22%	17%	<u>5%</u>
3=	Strategies not tailored for the individual client or neurodivergent people (e.g., not tailored for individual needs or preferred goals; neurotypical strategies do not always work for Autistic people)	19%	10%	<u>9%</u>
3=	Trivialising or not believing someone's autism diagnosis or their lived experience (e.g., not believing someone's experience)	19%	10%	<u>9%</u>
3=	Prohibitive cost (e.g., very expensive; services able to charge too much)	19%	28%	<u>-9%</u>

Rank	Problems experienced by Autistic people in relation to mental health services	% who stated this answer		
		Autistic people with high or complex disability needs <i>n</i> = 27	Entire Autistic sample <i>n</i> = 250	% difference
3=	Lack of knowledge or understanding of autism/neurodiversity, its presentation, and its impact across the lifespan (e.g., lack of knowledge about autism in females; lack of understanding of lived experience)	19%	28%	<u>-9%</u>
4	Professionals may make assumptions or have pre-conceived ideas of autism, holding a deficit-based view (e.g., stereotyping; behaviours viewed as attention seeking)	15%	10%	<u>5%</u>
5=	Long or closed waitlists (e.g. long waiting time to access diagnostic services, psychologists, and psychiatrists; waiting lists exacerbate issues)	11%	19%	<u>-8%</u>
5=	Concerns about professional's therapeutic skills (e.g., lack of genuine care; discriminatory towards Autistic people)	11%	10%	1%
5=	Lack of autism training (e.g., lack of regular autism training; lack of training provided by Autistic people)	11%	5%	<u>6%</u>
6	Mistrust in mental health services, sometimes associated with previous poor outcomes (e.g., negative experience; sensory pain due to inappropriate therapy; lack of trust due to previous experience)	7%	3%	4%

3.7.2.1.2 Factors causing the problems experienced by Autistic people in relation to mental health services, as reported by Autistic people with high or complex disability needs

A total of 22 Autistic people with high or complex disability needs opted to answer this open-ended question on mental health services. Table 67 ranks the 10 most commonly reported factors that Autistic people with high or complex disability needs felt were causing the problems that Autistic people experience in relation to mental health services reported above. The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 67: Most frequently reported causes of the problems experienced by Autistic people in relation to mental health services, as reported by Autistic people with high or complex disability needs

Rank	Causes of the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic people with high or complex disability needs <i>n</i> = 22	Entire Autistic sample <i>n</i> = 213	% difference
1	Lack of, or poor quality of, training for mental health professionals (e.g., poor training; lack of training in diagnosing and treating autism appropriately)	27%	27%	0%
2	Concern about therapeutic skills and/or attitude (e.g., lack of respect; ableism; not allowing time to develop relationship; ignorance)	23%	17%	<u>6%</u>
3=	Strategies and practices considered insufficient, inappropriate, or poor quality (e.g., lack of awareness of how to modify practices; neuro-normative concepts of well-being applied to Autistic people)	18%	9%	<u>9%</u>
3=	Lack of knowledge or understanding of autism and neurodivergent conditions, its presentation, and its impact (e.g., lack of understanding the heterogeneous presentation of autism; lack of understanding of stresses associated with autism)	18%	28%	<u>-10%</u>
5=	Insufficient funding (generally) (e.g., lack of funding; funding shortfall)	14%	15%	-1%

Rank	Causes of the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic people with high or complex disability needs <i>n</i> = 22	Entire Autistic sample <i>n</i> = 213	% difference
5=	Challenges around diagnosis (e.g., late diagnosis; lack of acceptance of self-diagnosis; misdiagnosis of autism)	14%	6%	8%
4=	Professionals may make assumptions or have preconceived ideas of autism (e.g., Autistic people are not competent; autism is a “male diagnosis”)	9%	8%	1%
6=	Challenges with Medicare support (e.g., no funding for autism assessment/therapy for people older than 15 years; out of pocket cost too high)	5%	8%	-3%
6=	Overwhelmed system/professionals with insufficient resources (e.g., lack of resources; overwhelmed staff; time pressure)	5%	7%	-2%
6=	Lack of knowledge, understanding, or experience of co-occurring conditions including mental health, and their interaction with autism (e.g., lack of knowledge about, or experience with, mental health conditions, Autistic burnout)	5%	7%	-2%

3.7.2.1.3 Factors that could prevent or reduce the problems experienced by Autistic people in relation to mental health services, as reported by Autistic people with high or complex disability needs

A total of 22 Autistic people with high or complex disability needs opted to answer this open-ended question on mental health services. Table 68 ranks the 11 most commonly reported factors that Autistic people with high or complex disability needs reported could prevent or reduce the problems that Autistic people experience in relation to accessing mental health services reported above. The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 68: Most frequently reported factors that could prevent or reduce the problems experienced by Autistic people in relation to mental health services, as reported by Autistic people with high or complex disability needs

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic people with high or complex disability needs <i>n</i> = 22	Entire Autistic sample <i>n</i> = 199	% difference
1	Increase (access to) training for people working as mental health professionals to enhance their understanding of autism (and other neurodivergence), including training from Autistic people with lived experience (e.g., mandatory, regular training; Autistic informed/delivered training)	45%	46%	-1%
2=	Improve access to, and quality of, services (e.g., reduce the red tape; consideration of access for regional and rural areas; services for people with complex needs)	18%	9%	<u>9%</u>
2=	Increase funding and/or affordability of mental health services across the lifespan (e.g., government funded functional capacity assessment; price caps and/or rebates)	18%	19%	-1%
3=	Government reform and support of mental health sector (e.g., legislation around language use; better legislation for protecting clients against poor treatment)	14%	7%	<u>7%</u>

Rank	Factors that could prevent or reduce the problems Autistic people experience in relation to mental health services	% who stated this answer		
		Autistic people with high or complex disability needs <i>n</i> = 22	Entire Autistic sample <i>n</i> = 199	% difference
3=	More mental health professionals, including those specialising in autism, and those who are Autistic/ neurodivergent themselves (e.g., more doctors; more psychologists; create new roles and professions to support Autistic people; incentives for experts; alternative qualification pathways)	14%	19%	<u>-5%</u>
3=	Make access and use of services easier and more autism-friendly (e.g., alternative methods to book appointments, increased flexibility of appointments; environment)	14%	10%	4%
4=	Education to support the general public's understanding of autism (e.g., address stigma; publicity drives to debunk myths and attitudes)	9%	7%	2%
4=	Facilitate changes to practice to focus on strengths, neurodiversity-affirming care, and skills relevant to supporting Autistic people (e.g., use social model rather than medical model; neurodiversity-affirming practice)	9%	10%	-1%
4=	More co-produced research that provides evidence-based practices for neurodivergent people (e.g., include Autistic and neurodivergent people in research design; research needed into neuro-affirmative practice)	9%	7%	2%
4=	Improved pathways to diagnosis (e.g., quicker path to diagnosis; more psychologists able to diagnose)	9%	5%	4%
4=	Enhance the therapeutic skills and awareness of mental health professionals to support their work with Autistic clients (e.g., listen to [and believe] the client to identify challenges; account for possible challenges in identifying emotions or forming trust)	9%	11%	-2%

3.7.2.1.4 Factors that are working well, or have worked well, for Autistic people in relation to mental health services, as reported by Autistic people with high or complex disability needs

A total of 14 Autistic people with high or complex disability needs replied to this open-ended question. Table 69 ranks the nine most commonly reported factors that Autistic people with high or complex disability needs reported to be working well, or that have worked well, for Autistic people in relation to mental health services. The data are ranked from most frequently reported to least frequently reported, for this priority group.

Table 69: Most frequently reported factors that are working well, or have worked well, for Autistic people in relation to mental health services, as reported by Autistic people with high or complex disability needs

Rank	What is working well, or has worked well, in relation to Autistic people’s experiences with physical health services	% who stated this answer		
		Autistic people with high or complex disability needs <i>n</i> = 14	Entire Autistic sample <i>n</i> = 155	% difference
1	Nothing/not a lot	29%	25%	4%
2=	When alternative/flexible access are available (inc. making appointment and practice) (e.g., online chat services; alternative booking options such as leaving voice message or online portal)	21%	13%	8%
2=	A range of different approaches and modifications highlighting that no single approach is suitable for everyone (e.g., trauma-informed; assistance animals; art therapy; social skills sessions; psychotherapy; group sessions)	21%	6%	15%
4=	When you develop a safe, trusting, therapeutic relationship (e.g., feeling safe; building long-term relationship; continuity of care)	7%	5%	2%
4=	Understanding what is best for oneself and advocating for this (e.g., creating environments where Autistic people feel safe; finding a therapist who works for the individual; mental health services that give Autistic people agency, choice and empowerment; self-advocacy)	7%	4%	3%
4=	Increased awareness of autism/neurodiversity and benefits of mental health support (e.g., awareness of female presentation; prevalence of mental health conditions for Autistic people)	7%	1%	6%

Rank	What is working well, or has worked well, in relation to Autistic people's experiences with physical health services	% who stated this answer		
		Autistic people with high or complex disability needs <i>n</i> = 14	Entire Autistic sample <i>n</i> = 155	% difference
4=	When NDIS funding has been provided to support needs (e.g., NDIS can reduce mental health burden when all needs are covered; supportive NDIS plan manager)	7%	13%	<u>-6%</u>
4=	When you find the right mental health professional for you, who is often knowledgeable/experienced about autism and its associated needs (e.g., understands autism and neurodiversity; experience working with Autistic people)	7%	18%	<u>-11%</u>
4=	Accommodations to support Autistic people (e.g., informing clients of the steps; providing processing time; writing summaries of key ideas)	7%	6%	1%

3.7.2.2 Autism Connect dataset: Contacts relating to mental health

A total of 65 contacts to Autism Connect relating to Autistic people with high or complex disability needs were in relation to mental health. The most frequent mental health issues that the contact related to are reported within this section. Table 70 ranks the most frequent mental health-related issues people contacted the Autism Connect helpline to discuss. The data are ranked from most frequently reported to least frequently reported issues. Where there was a difference of 5% or more between the contacts related to Autistic people with high or complex disability needs and all Autistic people, the percentage difference is highlighted with bold and underlined text in the tables.

Table 70: Most frequent mental health-related issues raised in contacts to Autism Connect by, or related to, Autistic people with high or complex disability needs

Topic (contacts)	Mental health issue raised	% contacts for mental health-related issues		
		For Autistic people with high or complex disability needs <i>n</i> = 65	All contacts <i>n</i> = 1,514	% difference between groups
Seeking therapist (<i>n</i> = 57)	Psychologist	46.2%	55.2%	<u>-9.0%</u>
	Psychiatrist	24.6%	12.4%	<u>12.2%</u>
	Counsellor	7.7%	3.1%	4.6%
	Other or unspecified mental health support	7.7%	5.6%	2.1%
	General therapists (mental health reasons)	1.5%	0.8%	0.7%

Topic (contacts)	Mental health issue raised	% contacts for mental health-related issues		
		For Autistic people with high or complex disability needs <i>n</i> = 65	All contacts <i>n</i> = 1,514	% difference between groups
Advice (<i>n</i> = 8)	Mental health advice	10.8%	10.3%	0.5%
	Education advice relating to mental health	1.5%	1.7%	-0.2%

3.7.2.3 “Making therapy better” questionnaire

It was not possible to identify Autistic people with high or complex disability needs from the demographics collected in this study. This highlights a clear need to work with this community to further knowledge in this area.

3.7.3 Summary of existing data for Autistic people with high or complex disability needs

3.7.3.1 Summary of differences noted in the data for Autistic people with high or complex needs as compared to the data for the entire Autistic sample

The focus here is on any items that differed within datasets provided by, or in relation to, Autistic people with high or complex disability needs and the data for the entire Autistic sample. A general summary of the issues with health and mental health services raised by, or in relation to, Autistic people with high or complex disability needs is provided in Section 3.7.3.2.

There were 61 items in which the data for Autistic people with high or complex disability needs differed substantially compared to the entire sample of Autistic people; 38 related to physical health care service experiences, and 23 related to mental health care service experiences (see Figure 12, Figure 13, Figure 14, and Figure 15). The process used to identify the substantial differences are documented in the method section. This large number of differences highlights that the experiences of people with high or complex disability needs accessing physical health care and mental health care services in Australia need further exploration through in-depth discussions or focus groups.

It is challenging to synthesise the items when there are so many substantially different whilst also acknowledging the scale and breadth of the issues raised by, or in relation to, this priority group. The items were where the data provided by, or in relation to, Autistic people with high or complex disability needs substantially differed from the entire sample of Autistic people in the same dataset. They tended to focus upon the importance of communication, including the option for multiple modes of communication, ensuring that all people communicating (be that the Autistic person or a family/carer) feel heard, believed and valued, and health care providers asking questions to gain from the experience of the Autistic person or their supporters. There were also a number of items that highlighted the importance of accommodations, and of the importance of finding and then developing a good relationship with a practitioner with the skillset to work with Autistic people with high or complex disability needs.

For physical health services, substantially less Autistic people with high or complex disability needs say that nothing is working.

Figure 12: Summary of substantial differences in existing datasets reporting on physical health service experiences for Autistic people with high or complex disability needs

In relation to physical health services, Autistic people with high or complex disability needs were more likely to...

- ▲ Make contact with Autism Connect, or have contact made about them, for assistance finding a health professional beyond a GP (+18.1%).
- ▲ Report the provision of increased communication options to improve access to, and information about, health care as working/having worked (+16%; “1,000 insights” survey).
- ▲ Report physical health care providers dismissing or not believing the reports of Autistic people or their family members (including not believing the person is Autistic) as a problem (+15%; “1,000 insights” survey).
- ▲ Report that problems could be reduced through government reform, support, and guidance (+14%; “1,000 insights” survey).
- ▲ Report that finding the right physical health provider for you, who was often described as knowledgeable about autism, understanding, caring, patient, and non-judgemental as working/having worked (+12%; “1,000 insights” survey).
- ▲ Report that problems are caused by dismissing or excluding an Autistic person or their family (+11%; “1,000 insights” survey).
- ▲ Report the provision of comfortable and sensory-friendly waiting areas as working/having worked (+11%, “1,000 insights” survey).
- ▲ Report professionals’ therapeutic skills as a problem (+11%; “1,000 insights” survey).
- ▲ Report when providers ask questions and listen to Autistic people and/or their family members and include Autistic individuals and their families in health care decisions as working/having worked (+9%; “1,000 insights” survey).
- ▲ Report that problems could be reduced by listening, validating and taking concerns of Autistic individuals and their families/carers seriously (+8%; “1,000 insights” survey).
- ▲ Report challenges accessing sufficient funding to support physical health as a problem (+8%; “1,000 insights” survey).
- ▲ Report that problems are caused by lack of communication accommodations (+7%; “1,000 insights” survey).
- ▲ Report that problems could be reduced by changing the diagnostic criteria for autism and diagnostic processes (+7%; “1,000 insights” survey).
- ▲ Report a lack of health professionals and services, and disparity based on location (i.e., regional and rural), as a problem (+7%; “1,000 insights” survey).
- ▲ Report that problems are caused by health professionals’ reluctance to adapt practices or provide accommodations/supports for Autistic individuals (+7%; “1,000 Insights” survey).
- ▲ Report that problems are caused by staff in health care settings (including administrative settings) having a lack of knowledge or understanding of autism/neurodiversity, diversity of presentations, and how autism/neurodivergence may impact physical health needs or symptoms, such as pain (+6%; “1,000 insights” survey).
- ▲ Report that problems could be reduced by increasing continuity of care, coordination of care and communication between service providers and care teams (+6%; “1,000 insights” survey).

- ▲ Report poor clinical decisions as a problem (+6%; “1,000 insights” survey).
 - ▲ Report that problems are caused by neurotypical/majority needs being prioritised, ableism, and a lack of neurodiversity affirming practice (+6%; “1,000 Insights” survey).
 - ▲ Make contact with Autism Connect, or have contact made about them, for assistance finding a GP (+5.3%).
 - ▲ Report problems could be reduced by enhancing the therapeutic skills and awareness of health care professionals to support their work with Autistic clients (+5%; “1,000 insights” survey).
 - ▲ Report when health care services are affordable and there is access to funding (beyond NDIS) as working/having worked (+5%; “1,000 insights” survey).
 - ▲ Report that problems are caused by systems being too complex to access and a lack of support, resources and/or education to access physical health services (+5%; “1,000 Insights” survey).
 - ▲ Report that problems could be reduced by increasing communication options to improve access to health care and access to information about health care (+5%; “1,000 Insights” survey).
 - ▲ Report when there are improved health services and practices as working/having worked well (+5%; “1,000 insights” survey).
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Figure 13: Summary of substantial differences in existing datasets reporting on physical health service experiences for Autistic people with high or complex disability needs

In relation to physical health services, Autistic people with high or complex disability needs were less likely to...

- ▼ Report that problems could be reduced by creating sensory-friendly physical health services or settings, including training to inform health care professionals of how overwhelming these environments can be for Autistic people and the impact this may have on their appointment (-5%; “1,000 insights” survey).
 - ▼ Report differences or difficulties with communication, including Autistic people experiencing challenges with describing their experiences, having to frequently repeat information to providers, and physical health providers not presenting information in a way that is accessible to Autistic people as a problem (-5%; “1,000 insights” survey).
 - ▼ Report problems could be reduced by increasing funding/resources and/or affordability of health services across the lifespan (-6%; “1,000 insights” survey).
 - ▼ Report that problems could be reduced by increasing the number of health care professionals and services available (-7%; “1,000 insights” survey).
 - ▼ Report the sensory elements of physical health services or settings (including waiting rooms and emergency departments) are not supportive for Autistic people, sometimes leading to sensory overwhelm (-7%; “1,000 insights” survey).
 - ▼ Make contact with Autism Connect, or have contact made about them, for assistance finding a paediatrician (-7.6%).
 - ▼ Report that nothing/not a lot is working well or has worked well (-11%; “1,000 insights” survey).
 - ▼ Make contact with Autism Connect, or have contact made about them, for assistance finding information on nutrition or dietetics (-15.6%).
 - ▼ Report lack of funding for autism education, training, and upskilling of physical health care professionals, as a problem (-16%; “1,000 insights” survey).
 - ▼ Rate challenges getting enough help with paperwork or forms as a low scoring barrier to acute physical health care (-0.26; “Barriers to care” questionnaire).
 - ▼ Report problems could be reduced by increasing (access to) education, training, and upskilling programs for health care professionals and administrative staff about autism, characteristics, and health impacts (-18%; “1,000 insights survey).
 - ▼ Rate doctors not believing in home or traditional remedies as a low scoring barrier to acute physical health care (-0.29; “Barriers to care” questionnaire).
 - ▼ Rate doctors or nurses not being fluent in their language as a low scoring barrier to acute physical health care (-0.35; “Barriers to care” questionnaire).
-

Figure 14: Summary of substantial differences in existing datasets reporting on mental health service experiences for Autistic people with high or complex disability needs

In relation to mental health services, Autistic people with high or complex disability needs were more likely to...

- ▲ Report a lack or, or poor quality of, training for mental health professionals as a cause of problems (+16%; “1,000 insights” survey).
 - ▲ Report a range of different approaches and modifications, highlighting that no single approach is suitable for everyone, as working/having worked (+15%; “1,000 insights” survey).
 - ▲ Report misdiagnosis of autism and/or co-occurring conditions as a problem (+14%; “1,000 insights” survey).
 - ▲ Make contact with Autism Connect, or have contact made about them, for assistance finding a psychiatrist (+12.2%).
 - ▲ Report strategies not being tailored for the individual client or neurodivergent people as a problem (+9%; “1,000 insights” survey).
 - ▲ Report insufficient, inappropriate, or poor-quality strategies and practices as a cause of problems (+9%; “1,000 insights” survey).
 - ▲ Report trivialising or not believing someone’s autism diagnosis or their lived experience as a problem (+9%; “1,000 insights” survey).
 - ▲ Report that problems could be reduced by improving access to, and quality of, services (+9%; “1,000 insights” survey).
 - ▲ Report challenges around diagnosis as a cause of problems (+8%; “1,000 insights” survey).
 - ▲ When alternative/flexible access are available as working/having worked (+8%; “1,000 insights” survey).
 - ▲ Report that problems could be reduced by government reform and support of the mental health sector (+7%; “1,000 insights” survey).
 - ▲ Increased awareness of autism/neurodiversity and benefits of mental health support as working/having worked (+6%, “1,000 insights” survey).
 - ▲ Report concern about therapeutic skills and/or attitude as a cause of problems (+6%; “1,000 insights” survey).
 - ▲ Report lack of autism training as a problem (+6%; “1,000 insights” survey).
 - ▲ Report insufficient availability/access of appropriate services as a problem (+5%; “1,000 insights” survey).
-

Figure 15: Summary of substantial differences in existing datasets reporting on mental health service experiences for Autistic people with high or complex disability needs

In relation to mental health services, Autistic people with high or complex disability needs were less likely to...

- ▼ Report that problems could be reduced by more mental health professionals, including those specialising in autism, and those who are neurodivergent themselves (-5%, “1,000 Insights” survey).
 - ▼ Report when NDIS funding has been provided to support needs as something that is working/has worked well (-6%; “1,000 insights” survey).
 - ▼ Report long or closed waitlists as a problem (-8%; “1,000 insights” survey).
 - ▼ Report prohibitive cost as a problem (-9%; “1,000 insights” survey).
 - ▼ Make contact with Autism Connect, or have contact made about them, for assistance finding a psychologist (-9%).
 - ▼ Report lack of knowledge or understanding of autism/neurodiversity, its presentation, and its impact across the lifespan as a problem (-9%; “1,000 insights” survey).
 - ▼ Report lack of knowledge or understanding of autism/neurodiversity, its presentation, and its impact across the lifespan as a cause of problems (-10%; “1,000 insights” survey).
 - ▼ Report finding the right mental health professional for you, who is knowledgeable/experienced about autism and its associated needs, as something that is working/has worked well (-11%; “1,000 insights” survey).
-

3.7.3.2 Summary of issues or experiences with physical and/or mental health services for Autistic people with high or complex disability needs, as reported across the datasets

Perspectives common across physical and mental health service experiences: Commonalities in the problems identified by Autistic people with high or complex disability needs across the physical and mental health service domains include:

- (a) concerns about the **therapeutic skills** of professionals
- (b) professionals **dismissing or not believing** the experiences of Autistic people
- (c) **strategies** or accommodations not being provided to support Autistic people
- (d) professionals holding a **limited knowledge of autism** and its presentation
- (e) **challenges accessing** appropriate services.

All themes reported above were echoed in both what Autistic people with high or complex disability needs perceive to be the causes of these problems, and strategies that could be used to reduce them. Specifically, many people identified that **professionals made assumptions about or dismissed the lived experience and/or autism diagnosis** of Autistic people. This could be linked with the commonly reported **lack of autism knowledge held by professionals or the quality and/or quantity of autism training** they receive. This reported lack of knowledge and/or training may therefore be linked to adjustments, accommodations, or tailored support not being provided to Autistic people.

By increasing the ease of access and quality of autism training and education for professionals, the resulting **knowledge could: enhance the therapeutic skills of providers; assist providers in understanding and recognising the lived experience of Autistic people and their families; and assist professionals in tailoring their approach** to better support Autistic people. Ideally, this training should be informed by co-produced research that provides evidence-supported practices for neurodivergent people, and should encompass information on autism and neurodiversity, its presentation, co-occurring conditions, and how the co-occurring conditions interact with autism.

Increased autism knowledge could also support professionals and services to make **accessing these services easier for Autistic people**, whether this is providing resources to inform people about processes and what to expect, providing support in completing paperwork and forms, offering alternative access pathways (e.g., online booking), or increasing communication options (e.g., augmentative and alternative communication), amongst other strategies.

Further factors that were raised by, or in relation to, Autistic people with high or complex disability needs were the need for **increase funding and/or affordability** to support access to these health care services, and an **increase in the number of professionals or services** with autism knowledge across these two health care domains.

3.7.4 Summary

A large number ($n = 61$) of substantial differences were observed between the experiences of Autistic people with high or complex disability needs and the entire sample of Autistic people within the datasets. This highlights the importance of working with Autistic people within this priority group to better understand their experiences and ways that assistance can be provided to better support access to, and use of, health care services within Australia. This need is further emphasised given that only a relatively small number of respondents from these large datasets were identified as having high or complex needs. Connecting and listening to the experiences of people from this priority group will enable services to be better placed to understand the reason for the differences in the perspectives and experiences of Autistic people with high or complex disability needs compared to the entire sample of Autistic people in this study.

That we found commonalities across the physical and mental health service domains highlights the robust nature of these challenges experienced by Autistic people with high or complex disability needs. These commonalities provide ideal starting points for improvements to these service domains that could be beneficial for Autistic people with high or complex disability needs in Australia.

As not all of the pre-existing datasets reported detailed respondent demographics, it was not always possible to identify the data reporting on those with high or complex needs. Future work should ensure that detailed respondent demographics are collected, as this can allow for a better understanding of this priority group and their experiences.

Our values



Inclusion

Valuing lived experience



Innovation

Solutions for long term challenges



Evidence

Truth in practice



Independence

Integrity through autonomy



Cooperation

Capturing opportunities together



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Independent national source of evidence for best practice



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